Evaluation of outcome measures in a brain injured population

Sarah Frances Cudmore

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CONTENTS

TABLES

FIGURES

ABBREVIATIONS

Abbreviations throughout the text.

Abbreviation	Meaning
AAH	Astley Ainslie Hospital
ADL	Activities of Daily Living
A&E	Accident and Emergency
CHI	Community Health Index
CIQ	Community Integration Questionnaire
CSF	Cerebrospinal Fluid
CT	Computed Tomography
DAI	Diffuse Axonal Injury
DRS	Disability Rating Scale
EDH	Extradural Haematoma
EHIEC	European Head Injury Evaluation Chart
ERSS	Edinburgh Rehabilitation Status Scale
FIM+FAM	Functional Independence Measure and Functional Assessment Measure
FLP	Functional Limitations Profile
GCS	Glasgow Coma Scale
GOAT	Galveston Amnesia and Orientation Test
GOS	Glasgow Outcome Scale
GP	General Medical Practitioner
ICD	International Classification of Disease
ICH	Intracerebral Haematoma
ICIDH	International Classification of Impairments, Disabilities And Handicaps
ICP	Intracranial Pressure
KAS-R1	Katz Adjustment Scale Relatives Questionnaire
MOS	Medical Outcomes Survey
MRI	Magnetic Resonance Imaging
PECS	Patient Evaluation Conference System

Abbreviation	Meaning
PTA	Post Traumatic Amnesia
QoL	Quality of Life
RIE	Royal Infirmary of Edinburgh
RTA	Road Traffic Accident
SAH	Subarachnoid Haemorrhage
SDH	Subdural Haematoma
SEM	Standard Error of the Mean
SF-36	Short Form 36
SIP	Sickness Impact Profile
TBI	Traumatic Brain Injury

ABSTRACT

Traumatic brain injury (TBI) is common with a peak incidence in young adults. Those who survive the initial insult are often left with a combination of mental and physical disabilities with associated social and vocational handicap that may persist or change over many years. The natural history of post-injury progress is poorly understood and there is increasing demand from clinicians and other service providers for accurate assessment of the outcome of TBI. This thesis addresses the longitudinal study of TBI outcome using different measures, modes of data collection and time intervals since injury in three studies.

The first study evaluated a new outcome measure, the European Head Injury Evaluation Chart (EHIEC), purported to be a simple and reliable means of comprehensively assessing the TBI patient from insult to several years post-injury. Forty seven patients were interviewed using this measure at discharge from a rehabilitation unit in Edinburgh and a subgroup (n=35) were examined at 15 months post-injury. Although the current form of the EHIEC has some useful components, it was found to be too long with poor item definition and insufficient guidelines to be accepted for widespread use.

Relatively few studies have focused on outcome following TBI many years after injury. It was evident from the first study that the EHIEC would not be a practical and reliable tool to assess outcome at a later stage and therefore two alternative approaches were used - an interview study and a larger postal survey which assessed patients between five and twelve years after injury. The interview study (n=78) used a variety of disease specific and generic outcome measures [including the Glasgow Outcome Scale (GOS), Functional Assessment Measure (FIM+FAM), Community Integration Questionnaire (CIQ), Edinburgh Rehabilitation Status Scale (ERSS), Short Form 36 (SF-36) and Functional Limitations Profile (FLP)] whilst the postal survey (n=525) included the GOS, SF-36 and FLP. Although the SF-36 has been used with many other populations, results had not been reported for the traumatically brain injured.

Few statistically significant results were found between the age and injury severity groups for the various outcome measures but this, in itself, is a novel finding. The lack of differences between the severity groups may indicate that outcome tends to converge over time; that the Glasgow Coma Scale, which was used to determine severity of injury, is not a valuable predictor of outcome in the longer term; or that the measures used were not sufficiently sensitive for this setting. These studies have demonstrated that three of the

measures (i.e. GOS, FIM+FAM, EHIEC) have serious limitations for longitudinal use. In contrast the CIQ, ERSS and SF-36 provide interesting material on aspects of outcome although were also found to be have disadvantages such as missing data and substantial ceiling effects.

Whilst this thesis has not found an ideal multidimensional measure for assessment following TBI it has contributed to the field of outcome and provided valuable data on the long term follow up of this population.

THESIS STRUCTURE

This thesis focuses on the assessment of health outcome following traumatic brain injury (TBI), particularly in the long term. Three research studies involving different patients have been undertaken, including the assessment of the utility of a recently developed measure, the European Head Injury Evaluation Chart, and the long term follow up of TBI patients by face-to-face interview and postal survey. The structure of the thesis is detailed below.

Chapter One provides an introduction to TBI, including its definition, classification and assessment of severity. The mechanisms of brain injury and development of damage are discussed followed by an overview of the main cranial and intracranial lesions.

Chapter Two provides an overview of the epidemiology of TBI. Outcome following this insult is introduced with a review of the major studies of long term follow up. Finally the various sources of information and methods of data collection are discussed.

Chapter Three is the first of the original research chapters and provides an assessment of the utility of a newly developed outcome measure, the European Head Injury Evaluation Chart. Forty seven patients are assessed at discharge from a rehabilitation unit, and a subgroup of 35 are followed up at 15 months post-injury. Results are presented plus a critical review of the measure.

Chapters Four and Five describe the follow up study of 78 TBI patients, 5-11 years after injury. Data are collected from the patient and relative by face-face interview. Chapter Four details the study methodology and patient population and Chapter Five provides the results and discussion.

Chapters Six and Seven describe a postal follow up study of 525 TBI patients, 5-12 years after injury. Chapter Six details the study methodology and patient population and Chapter Seven provides the results and discussion.

Chapter Eight is the concluding chapter to this thesis and provides a general review of the findings.

Chapter One

Introduction to traumatic brain injury

1.1 INTRODUCTION

Traumatic brain injuries (TBI) constitute a major health problem throughout the world resulting in substantial mortality and morbidity (Komatsu et al. 1979; Jennett, 1996). It is estimated that of those patients who are hospitalised and survive, one in five will suffer significant long-term disability (Kraus and Sorenson, 1994) but can expect a near normal life expectancy (Anonymous, 1990; Powell, 1994). All areas of a survivor's life may be affected from their physical health to emotional, cognitive, behavioural and social aspects.

In the United States, Japan and several European countries including the UK, it has been estimated that more years of life are lost in males below the age of 65 from trauma than from cardiac or cerebrovascular disease (Rockett and Smith, 1987). This reflects the scale of traumatic injuries and the young age of many victims. As the TBI population is dominated by the young adult male, the economic impact of this tragedy on society must be recognised as the indirect costs of this event are substantial (Max et al. 1991).

The aim of this thesis is to attempt to measure outcome of TBI in a longitudinal way. The first approach uses the recently developed European Head Injury Evaluation Chart as a comprehensive tool, and the second method uses a group of standardised measures administered by interview and postal survey.

1.2 DEFINITION OF TRAUMATIC BRAIN INJURY

One might assume that the basic definition of a TBI would be straightforward, however this is not so. Given the range of injury severity, from individuals who do not seek medical attention to those who are killed instantly, providing a definition is a difficult task (Jennett, 1996). Attempting to separate head injuries from brain injuries is a problem particularly at the less severe end of the spectrum (Sorenson and Kraus, 1991). These terms are often used interchangeably, although brain injuries are more accurately a subset of head injuries (Kraus and McArthur, 1996). However, the distinction is not clear-cut and many studies include individuals with a head injury but no brain lesion alongside those who have sustained an injury to the brain (Sorenson and Kraus, 1991).

Some authors propose that only those with a definite history of loss of consciousness, post-traumatic amnesia and mental confusion should be given the diagnosis of a brain injury (Kraus et al. 1984; Kraus and McArthur, 1996). However, recent evidence has suggested

that even those with a seemingly mild injury, without clinical complications, may in fact have structural damage noted on computed tomography (CT) or magnetic resonance imaging (MRI) scan and some patients may develop serious complications (Jenkins et al. 1986; Stein and Ross, 1992). From a broader perspective it is important to include all injuries, irrespective of severity, when studying causation and prevention as many mild injuries might have been more serious in slightly different circumstances. The lack of an agreed definition for TBI is a fundamental problem in this field of research (Kraus and McArthur, 1996).

1.3 CLASSIFICATION OF TRAUMATIC BRAIN INJURY

The classification of TBI is a complex and controversial area and various subdivisions are used. One common method separates injuries into 'closed' and 'open', therefore differentiating those that do not expose the contents of the skull from those in which the dura mater is torn and the contents of the skull are exposed (Richardson, 1990b). This subdivision is potentially relevant when deciding upon immediate medical management. The commonly accepted usage of the term closed injury describes cases in which there is no penetration of the skull, although a skull fracture may be present. This would most frequently arise as a result of rapid acceleration or deceleration of the head and may involve contact with a blunt, immobile object or surface (Richardson, 1990b). Using the term closed injury in this manner distinguishes it from a penetrating injury caused by a sharp instrument or missile. This thesis deals only with closed head injuries.

The International Classification of Diseases (ICD) (World Health Organisation, 1977) is the main means of producing official statistics on hospital admissions and deaths in many countries. In the ninth edition head and brain injuries are covered by ten rubrics (Table 1.1), however there are several problems in using this system that limit its accuracy. For instance, the rubrics are based on pathological rather than clinical criteria, and each category is not mutually exclusive (Jennett and Teasdale, 1981). For example, a common pathology such as an intracranial haematoma tends to be associated with a skull fracture, but it is classified by a rubric that excludes such fractures. It is also difficult to ascertain severity of TBI from ICD codes.

Table 1.1 International Classification of Disease (Ninth revision)

ICD code	Definition
	Fracture of skull, spine and trunk (N800-N09)
N800	Fracture of vault of skull
N801	Fracture of base of skull
N802	Fracture of facial bones
N803	Other and unqualified skull fractures
N804	Multiple fractures involving the skull or face with other bones
	Intracranial injury (excluding those with skull fractures)
N850	Concussion
N851	Cerebral laceration and contusion
N852	Subarachnoid, subdural and extradural haemorrhage following injury (without mention of laceration or contusion)
N853	Other and unspecified intracranial haemorrhage following injury (without mention of laceration or contusion)
N854	Intracranial injury of other and unspecified nature

The usefulness of the data for case ascertainment must also be questioned. For example, in the National Head and Spinal Cord Injury Survey in the United States almost two thirds of cases selected by ICD codes were subsequently excluded when discharge summaries were reviewed (Kalsbeek et al. 1980). Although ICD codes may allow comparison between studies, revisions to the coding structure between ICD-9 and the latest version, ICD-10 (World Health Organisation, 1992), may present difficulties.

1.4 ASSESSMENT OF TRAUMATIC BRAIN INJURY SEVERITY

GLASGOW COMA SCALE

The most commonly used method of determining the severity of TBI in the acute setting is the Glasgow Coma Scale (GCS). The GCS was developed in the 1970's to ascertain the patient's conscious level following TBI (Teasdale and Jennett, 1974). It was originally a 14 point scale but has since been revised to the current 15 point version (Teasdale and Jennett, 1976). The GCS has been accepted for widespread use and provides a reliable and rapid means of assessment (Teasdale et al. 1978) by recording the patient's best visual, verbal and motor responses and providing a separate score for each (Table 1.2).

Table 1.2 Glasgow Coma Scale

Eye opening		Motor response		Verbal response	
None	1	None	1	None	1
To pain	2	Extension	2	Incomprehensible	2
To speech	3	Abnormal flexion	3	Inappropriate	3
Spontaneous	4	Withdrawal	4	Confused	4
		Localising pain	5	Oriented	5
		Obeying commands	6		

Although there is some concern about the validity of summing the three response scores to provide a total of between three to fifteen (McKinlay and Brooks, 1984) it is common practice to do so. This total score is then used to categorise the severity of TBI into mild, moderate and severe as shown in Table 1.3 (Rimel et al. 1981; Rimel et al. 1982). Some authors have suggested alternative subdivisions (Stein and Ross, 1992) but the classification shown is that most widely used, where a GCS of eight or below indicates coma, defined as 'not obeying commands, not uttering words and not opening eyes' (Jennett and Teasdale, 1981).

Table 1.3 Severity of TBI by Glasgow Coma Scale score

Severity of TBI	GCS score
Mild	13-15
Moderate	9-12
Severe	3-8

Assessment of Glasgow Coma Scale score

There are a number of difficulties in using the GCS, one of which relates to the timing of assessment to classify injury severity. Scores may have been taken at the scene of the injury, in Accident and Emergency (A&E), pre or post-resuscitation or at some ill-defined point in time after injury (Kraus and Sorenson, 1994). In addition to variation in timing of assessment, some researchers quote the best GCS score within a certain time period whilst others use the worst score (Hall and Johnston, 1994). It is becoming increasingly common to record the score at six hours post-injury, as recommended by Teasdale and Jennett (1976), as this will usually be post-resuscitation and the effects of alcohol will be minimised. In cases where the patient has been intubated, a pre-intubation score is required. In many instances, however, information relating to timing and method of GCS assessment is not available from clinical notes or published studies.

Assessment of GCS in cases of mild TBI can be particularly problematic. Although the subject may have been disoriented immediately after the accident, full consciousness may have been regained by the time of presentation to hospital (Richardson, 1990b). It has also been suggested that the upper levels of the GCS may be less useful at determining severity of injury and outcome (Dacey et al. 1986; Gomez et al. 1996; Jennett, 1996). Despite its limitations, the GCS does provide an objective, independent assessment of TBI severity which is particularly useful in assisting acute management decisions (Vollmer et al. 1991). However, clear guidelines relating to the method of assessment would help standardise data in studies and allow comparison of results.

POST TRAUMATIC AMNESIA

Before the development of the GCS, the main method of assessing TBI severity was the length of post-traumatic amnesia (PTA) which was defined by Russell (1932) as the period of impaired consciousness. Post traumatic amnesia (PTA) is measured from the time of injury until the patient regains continuous memory, although estimation of its duration can be difficult as short episodes of intact memory may be present within the period of amnesia. Table 1.4 illustrates the classification of injury severity based on the duration of PTA as devised by Jennett and Teasdale (1981).

Table 1.4 Severity of TBI by duration of post-traumatic amnesia

Severity of TBI	Duration of PTA
Very mild	< 5 minutes
Mild	5-60 minutes
Moderate	1-24 hours
Severe	1-7 days
Very severe	1-4 weeks
Extremely severe	>4 weeks

Assessment of Post Traumatic Amnesia

Post traumatic amnesia can be ascertained prospectively or retrospectively. Retrospective assessment is the more traditional method and has the advantage of allowing a greater proportion of patients to be examined. However as there is no standardised procedure for retrospective estimation of PTA, techniques are likely to vary making comparison between studies difficult (Richardson, 1990b; Forrester et al. 1994). Therefore, it has been argued that regular assessment of the patient's orientation throughout the early post-injury period would provide a more accurate estimation of PTA (Forrester et al. 1994), and the Galveston Orientation and Amnesia Test (GOAT) (Levin et al. 1979b) was specifically developed for this purpose in the TBI population. The GOAT is a serially administered clinical measure that includes assessment of temporal and geographical orientation, biographical details and information relating to events before and after the injury. However it has been criticised for primarily being a measure of orientation rather than memory (Richardson, 1990b), for the time required for daily administration and because of assessment difficulties with aphasic patients. Overall the GOAT has provided a useful clinical method of measuring PTA in the absence of other simple instruments, and despite concerns about the consistency of its

usage, duration of PTA remains one of the most useful means of classifying severity of TBI and predicting outcome (Jennett et al. 1981; Wilson et al. 1994).

GLASGOW COMA SCALE VERSUS POST TRAUMATIC AMNESIA

An editorial in the Lancet concluded that, at that time, PTA was 'the best yardstick for assessing severity of head injury' (Editorial, 1961). The introduction of the GCS in the 1970's allowed for a more precise assessment of the conscious level at the time of injury. It is frequently assumed that coma depth and duration, and length of PTA, are closely related and reflect aspects of a common mechanism (Wilson et al. 1994). However, studies have shown that the relationship is only moderately close (Levin et al. 1984). This might be due to inconsistencies in measurement or because coma depth and PTA actually reflect different aspects of brain damage and are therefore not equivalent (Wilson et al. 1994).

Wilson et al. (1994) conclude that while the GCS is the preferred measure for initial assessment of severity, the duration of PTA yields a 'less specific, more global measure of brain damage than coma depth or duration'. In particular, there may be certain cases where PTA is helpful in providing additional information to indicate the severity of injury, for example where the coma is only of short duration but PTA is prolonged. Post traumatic amnesia may be particularly useful in mild head injury when alteration in conscious level may have resolved by the time of presentation to hospital (Kibby and Long, 1996), as PTA is always longer in duration than coma, occurs closer to the end point of recovery and can, if necessary, be assessed retrospectively.

1.5 MECHANISM OF INJURY AND DEVELOPMENT OF BRAIN DAMAGE

Knowledge of the mechanism of injury and development of damage to the head and brain following a traumatic insult may lead to greater understanding of the immediate and long-term effects of TBI.

MECHANISM OF INJURY

The main types of injury are contact and acceleration/deceleration (Ommaya and Gennarelli, 1974; Gennarelli and Thibault, 1982).

Contact injuries

As the name implies, contact injuries occur as a result of an object striking the head or the head striking a solid surface. Localised injuries tend to be present such as scalp lacerations, skull fractures (with or without an associated extradural haematoma), surface contusions or lacerations, and intracerebral haemorrhage affecting the underlying brain (Graham and McIntosh, 1996).

Acceleration/deceleration injuries

In acceleration/deceleration injuries, the damage results from movement of the brain within the skull *after* the impact of injury, leading to intracranial and intracerebral pressure gradients as well as shear and compressive strains (Graham and McIntosh, 1996). Such inertial forces are responsible for two important injuries, the acute subdural haematoma and widespread damage to axons (Gennarelli and Thibault, 1982).

DEVELOPMENT OF BRAIN DAMAGE

There are two main stages in the development of brain damage after insult, primary and secondary (Adams et al. 1980; Graham and McIntosh, 1996). This classification is important clinically as it assists the identification of preventable complications following initial damage. The cranial and intracranial lesions listed below will be described in Section 1.6.

Primary damage

Primary damage occurs at the time of the injury and includes scalp lacerations, skull fractures, surface contusions and lacerations, diffuse axonal injury and intracranial haemorrhage (Graham and McIntosh, 1996).

Secondary damage

Secondary damage is produced by complex processes that are initiated at the moment of injury, but may not become clinically apparent for some time (Adams et al. 1980). It includes brain damage due to ischaemia, brain swelling, infection, raised intracranial pressure and the subsequent neurochemical changes induced by these events (Graham and McIntosh, 1996).

Clearly information relating to the pathology of brain damage is gathered from fatal cases included in post-mortem studies. The injuries of those who die following TBI may well differ from those who survive, and therefore one must be cautious when generalising results to the neuro-radiological and clinical features of survivors (Graham and McIntosh, 1996). Nevertheless, such studies are useful in defining the sequence of events between injury and death, and enhancing our knowledge of the types of damage present in survivors who have residual disabilities (Adams et al. 1980). It is now thought that damage only identifiable at a microscopic level may be responsible for cerebral dysfunction and death. However the need for proper fixation of brain tissue soon after death and for a skilled neuropathologist to examine the specimens, means that there are few quality studies of large series of patients. The pressures of time and lack of the required expertise mean that the macroscopic rather than microscopic abnormalities are often relied upon at post-mortem, hence obscuring the true cause of death (Adams et al. 1980).

1.6 CRANIAL AND INTRACRANIAL LESIONS

Increased use of specialised neuroradiological techniques (mainly CT and MRI) has allowed damage to be classified into focal and diffuse.

FOCAL LESIONS

Focal lesions include scalp lacerations, skull fractures, surface contusions and lacerations, intracranial haematoma and consequences such as raised intracranial pressure (Graham and McIntosh, 1996). Such lesions tend to cause neurological dysfunction by local brain damage or by creating a mass effect which may lead to brain shift, herniation and eventually to brainstem compression (Gennarelli, 1987).

Scalp lacerations and skull fractures

Although these lesions affect the scalp and skull rather than the brain itself, they are included here because of their associated complications. Scalp lacerations may indicate the site of impact, be associated with an underlying fracture or may act as routes for intracranial infection. Skull fractures may be linear or depressed and involve the vault and/or the base of the skull (Currie, 1993). They may be associated with serious complications such as intracranial haematoma, especially when there is an alteration in conscious level (Mendelow et al. 1983), although severe neural injury may occur in the absence of a skull fracture (Cooper, 1987).

Surface contusions and lacerations

These haemorrhagic lesions have traditionally been considered the hallmark of brain damage caused by traumatic injury (Adams et al. 1980), although they need not necessarily be present (Graham and McIntosh, 1996). The main difference between a contusion and a laceration is that the former has an intact pia-arachnoid, whereas it is torn in the latter. Contusions and lacerations can be difficult to differentiate because their distribution is inclined to be similar. They tend to be most severe on the crests of the gyri and characteristically affect the inferior aspects of the frontal and temporal lobes where the brain comes in contact with the bony prominences of the base of the skull (Adams et al. 1980). Acutely, the lesions may involve the loss of blood and become swollen but with time they become golden-brown shrunken scars (Graham et al. 1987; Graham and McIntosh, 1996).

Intracranial haemorrhage

Intracranial haemorrhage remains one of the most important components of TBI and is associated with high morbidity and mortality (Vollmer et al. 1991). The clinical effects are often delayed as it is the associated brain swelling that is partially responsible for subsequent events (Jennett et al. 1977; Graham and McIntosh, 1996). Intracranial haemorrhage includes subarachnoid haemorrhage (SAH), extradural haematoma (EDH), acute and chronic subdural haematoma (SDH), and intracerebral haematoma (ICH) and contusions.

Subarachnoid haemorrhage

Subarachnoid haemorrhage (SAH) is the most common form of intracranial haemorrhage associated with TBI. The subarachnoid collection of blood is caused by the shearing of the microvessels within the subarachnoid space during the acceleration/deceleration phase of brain movement (Lowe and Northrup, 1996). In the absence of other more serious lesions, the SAH is often a fairly benign pathology.

Extradural haematoma

Extradural haematomas (EDH) are thought to develop because of injury to the middle meningeal artery or veins, or rarely due to laceration of the dural venous sinuses (Lowe and Northrup, 1996). They tend to be more common in the young to middle aged. Patients typically present following blunt trauma of sufficient force to cause a skull fracture although this need not be present (Lowe and Northrup, 1996). There may be little other evidence of brain damage (Graham and McIntosh, 1996) and characteristically the patient suffers a sudden deterioration in conscious level with the development of localising signs.

Acute subdural haematoma

The acute subdural haematoma (SDH) develops because of bleeding from the bridging veins in the subdural space (Gennarelli and Thibault, 1982). Compared with other types of intracranial haematomas, the acute SDH has the most significant association with severe injury, poor outcome and difficult clinical management (Gennarelli and Thibault, 1982; Lowe and Northrup, 1996). There is likely to be soft tissue injury at the site of impact, localising signs and evidence of trauma to the rest of the body (Lowe and Northrup, 1996). Patients most commonly present with an immediate and notable alteration in conscious level following a moderate to severe blow to the head, or less commonly, an acceleration/deceleration injury.

Chronic subdural haematoma

Although it is assumed that most chronic SDHs were once acute, the two lesions are clinically quite distinct. The typical presentation is an elderly patient with a history of mild or repeated trauma in the previous weeks or months, headache, confusion and decreased level of responsiveness (Lowe and Northrup, 1996). It is thought that an acute bleed will have occurred at some stage from the bridging veins in the subdural space which become vulnerable to relatively minor trauma because of the degree of atrophy in the elderly brain. A chronic SDH may establish itself slowly over a period of time hence the gradual onset of symptoms (Lowe and Northrup, 1996).

Intracerebral haematomas and contusions

Intracerebral haematomas (ICH) and contusions represent a considerable source of morbidity and mortality following TBI (Foulkes et al. 1991). It is difficult to distinguish between the two lesions either clinically or radiologically although they tend to be managed in a similar fashion and have comparable outcomes (Lowe and Northrup, 1996). The formation of an ICH is thought to be due to the impact rupture of the intracerebral veins and arteries. As with the lesions discussed above, the size and location of the ICH or contusion tends to dictate the severity of neurological deficit in the patient. Larger lesions may be associated with other intracranial pathologies, such as an EDH or SDH.

Raised intracranial pressure

Raised intracranial pressure (ICP) tends to be caused by space occupying lesions such as haematomas (i.e. EDH, SDH) and their associated brain swelling. The expansion of the mass lesion leads to deformation of the brain tissue, a decrease in the volume of cerebrospinal fluid (CSF) and subsequent shift and distortion of the brain (Graham and McIntosh, 1996). Within the confines of the closed skull this may result in brain herniation (e.g. of the cingulate gyrus beneath the free edge of the falx, the parahippocampal gyrus through the opening of the tentorium cerebelli, or the cerebellar tonsil through the foramen magnum). With the formation of internal herniae the basal cisterns are obliterated and pressure gradients develop between the various intracranial compartments. This eventually leads to secondary damage with the development of midline haemorrhages or infarcts in the brainstem or cerebellum. Such brain damage is a common complication of closed head injury and is thought to account for the deterioration and coma noted in those who die in the early weeks after injury (Galbraith, 1976).

DIFFUSE LESIONS

Diffuse lesions tend to cause more global disruption of neurological function and include diffuse axonal injury (DAI), ischaemic brain damage and brain swelling (Gennarelli, 1987; Graham and McIntosh, 1996).

Diffuse axonal injury

Diffuse axonal injury (DAI), 'the microscopic evidence of widespread damage to axons' (Graham and McIntosh, 1996), is thought to be a very significant factor relating to outcome in the brain injured patient (Adams et al. 1980). It is now believed that rather than being an all or nothing phenomenon, DAI may be present in varying degrees based on the duration of coma and brainstem signs (Gennarelli, 1987; Blumbergs et al. 1989). Adams et al. (1982), from the analysis of fatal cases of DAI in humans, and Gennarelli et al. (1982b) who induced DAI in primates, argue that there is a mechanical pathogenesis behind this lesion. Evidence such as the lower incidence of a lucid interval in those with DAI supports the belief that this lesion occurs at the time of insult and Adams et al. (1982) reason that DAI is therefore neither preventable nor reversible.

It is believed that shearing rather than compression injuries are the cause of most mechanically induced traumatic brain lesions. Shear strains develop in tissues because of differential movements of one part of the brain with respect to another, and it is thought that these strains are great enough to cause disruption of the nerve fibres (Holbourn, 1945; Adams et al. 1980). The work of Holbourn (1945), Ommaya and Gennarelli (1974) and Adams et al. (1980) indicate that it is rotational acceleration of the brain that is most important in producing the required type and magnitude of force to cause shear strain injuries. Experiments with primates (Gennarelli et al. 1982b) have re-inforced the findings of Holbourn and Adams and suggest that as depth of coma increases, severity of DAI also increases; recovery is inversely related to the extent of DAI; and the direction of the acceleration forces are important in the production of axonal injury.

Patients with DAI have distinctive clinico-pathological features with a lower incidence of a lucid interval, skull fractures, contusions, intracerebral haematoma and raised ICP (Adams et al. 1982). This may be partially explained by the types of insults associated with DAI which are primarily acceleration/deceleration injuries most typical of road traffic accidents, often in the absence of direct trauma (Adams et al. 1982; Gennarelli et al. 1982b; Adams et al. 1989). Diffuse axonal injury has also been reported in those who have sustained contact

injuries, for example falls from a considerable distance (Adams et al. 1984) or occasionally following assault although the mechanism here is not understood (Graham et al. 1992). There is also an association between DAI and the persistent vegetative state (Adams et al. 1980).

Ischaemic brain damage

In the last 20-30 years it has been recognised that ischaemic brain damage may be a consequence of TBI (Graham et al. 1989). It is thought that this damage primarily occurs as a result of a reduction in regional blood flow and there appears to be an association with episodes of hypoxia or raised ICP. There is increasing evidence that primary damage to the brain may be compounded by secondary insults that occur at the scene of the accident, during transfers or in the further management of the patient. Recent work has investigated these complications and their prevention (Jones et al. 1994).

Brain swelling

An increase in the volume of the brain is a common finding after TBI (Graham et al. 1987) and may be due to an expansion of cerebral blood volume (hyperaemia) or water content of the brain tissue (oedema) (Prow et al. 1996). It can be severe enough to cause a rise in ICP and may even cause brain shift and herniation. Brain swelling may be localised and associated with contusions or ICH or generalised affecting one or both cerebral hemispheres. Ipsilateral swelling may occur following the evacuation of a haematoma when the brain expands, via increased cerebral blood volume, to fill the space created (Adams et al. 1980).

DIAGNOSIS, INCIDENCE AND NEUROSURGICAL MANAGEMENT OF CRANIAL AND INTRACRANIAL LESIONS

Diagnosis

> 'the primary objective of the diagnostic radiologist in neurotraumatology is to provide diagnostic information crucial to clinical management in order to limit morbidity and mortality'
>
> (Gentry, 1994)

The diagnosis of cranial and intracranial lesions is mainly by specialised neuroradiological techniques although simple skull X-rays are still important. The main diagnostic tool is the CT scan as although MRI scanning may be more sensitive at detecting certain lesions, particularly in the brain stem, it is more costly and not widely available (Gentry, 1994; Prow et al. 1996). However if significant, intracranial haemorrhage is relatively simple to identify on CT scan and an associated mass effect or brain shift may also be evident (Lowe and Northrup, 1996). The diagnosis of DAI is often difficult as the CT scan may appear normal (Snoek et al. 1979; Prow et al. 1996), MRI cannot identify all cases (Gentry, 1994) and even at post-mortem the brain may have a virtually normal macroscopic appearance (Adams et al. 1980).

Incidence

It is difficult to estimate the incidence of cranial and intracranial lesions following TBI as the majority of studies concentrate on hospital admissions and are often not comparable. Jennett et al. (1979a) reported that of neurosurgical admissions in Scotland, 19% had sustained a depressed skull fracture and 35% had an intracranial haematoma (9% EDH, 23% SDH, 10% ICH). In the USA, the Traumatic Coma Data Bank published figures for the severely injured TBI population (Foulkes et al. 1991). In order to increase the relevance to the population studied in this thesis, those who suffered gun shot wounds were excluded but the following data relates to both children and adults. An intracranial lesion was present in 43% (6% EDH, 24% SDH, 10% ICH, 3% haemorrhagic contusions) and 56% had sustained diffuse injury. Of the skull fractures, 6% were compound, 29% were linear, 12% were depressed, 25% were basal and 14% had multiple skull fractures. Similar findings were reported by Gennarelli et al. (1982a).

Neurosurgical management

Neurosurgery is a highly specialised and skilled area and only a very brief overview is provided here. Following general resuscitation, the need for neurosurgical intervention will be assessed and undertaken as required. One of the most common procedures is a craniotomy and evacuation of an intracranial haematoma. In some cases, a burrhole may be used to drain the haematoma instead. An ICP monitor may be inserted at operation. For those not requiring immediate surgery, regular neurological review is essential and any deterioration or the development of localising signs indicates the need for further scanning as a delay in diagnosis and treatment may lead to increased mortality (Galbraith, 1976).

1.7 SUMMARY

This first chapter has introduced the field of TBI. It has provided an overview of its classification and highlighted the need for a precise definition of TBI. The two main means of assessing the severity of injury, namely the GCS and duration of PTA, have been introduced and their relative strengths and weaknesses discussed. The problems of when to assess the GCS score and the most appropriate method of measuring PTA have been highlighted, and the need for standardisation of these important assessments emphasised.

The main mechanisms of brain injury, contact and acceleration/deceleration, and the development of primary and secondary brain damage, have been described. It is clear that TBI may result in a wide range of neuropathological lesions some of which are more clearly understood than others. The most common lesions have been defined in this chapter as the relationship between brain damage and subsequent outcome, although complex, is of great clinical importance.

Chapter Two
Epidemiology and outcome

2.1 EPIDEMIOLOGY OF TRAUMATIC BRAIN INJURY

> 'The descriptive elements of the epidemiology of head injuries are woefully incomplete ... because no single report includes *all* patients with head injuries (irrespective of severity) within a defined population.'
>
> (Kraus, 1978)

Over the last 20 years, an increasing number of large epidemiological studies of TBI have been undertaken. Such studies are essential to estimate the extent of this type of injury and will assist both the planning of health care and the prevention of similar injuries in the future. However, reliable statistics are still difficult to obtain and much of the available international data relates to injury as a whole, rather than being specific to head, or brain, injury (Jennett, 1996).

SOURCES OF EPIDEMIOLOGICAL DATA

Various sources of data are available when studying the epidemiology of TBI including mortality data, hospital discharges, non-hospitalised cases and individual surveys.

Mortality data

As deaths are registered in most countries, mortality data provide a useful source of epidemiological material. However, they cannot always be relied upon for accuracy as most will be based upon clinical rather than pathological reports. There will be occasions when a death may be wrongly ascribed to a brain injury; where the cause is obscured by the term 'multiple injuries' or where the death does not occur acutely, a different cause may be given (Jennett and Teasdale, 1981). If classified consistently, this data provides a useful guide to mortality following TBI over time.

Routinely generated hospital discharge data

Data are published for all Scottish, and 10% of English and Welsh, hospital discharges providing information on age, duration of hospital stay, type of hospital and speciality (Jennett and Teasdale, 1981). However, data will only include diagnosed cases of TBI managed within the hospital system and inaccuracies similar to those described for the mortality data may occur.

Non-hospitalised cases

An unknown number of TBI cases may be overlooked as they do not seek or receive in-patient medical care. This is a particular problem in mild TBI as many patients will attend their General Medical Practitioner (GP) or A&E department without being admitted, and therefore will not be captured in the routinely generated hospital activity statistics. To provide a complete picture of TBI, it is vital that these cases are documented. Non-hospitalised cases of TBI are also important because there is evidence that mild injury may lead to significant consequences, but the frequency of such disability is unknown (Fife, 1987; Sorenson and Kraus, 1991). Studies have estimated that cases presenting to A&E may well outnumber admissions by four or five to one (Strang et al. 1978; Brookes et al. 1990) although it must be recognised that many of these cases will not fulfil the criteria for a TBI.

Individual surveys

A number of other surveys have been undertaken to increase the epidemiological knowledge of TBI, although the majority took place in the 1970's. Some have attempted to look at all head or brain injuries leading to hospitalisation and/or death (Scottish Head Injury Management Study, 1977; Kalsbeek et al. 1980) whilst others have looked specifically at severe injuries (Jennett et al. 1977; Foulkes et al. 1991).

INCIDENCE AND PREVALENCE OF TRAUMATIC BRAIN INJURY

Epidemiological terms

Some important epidemiological terms are defined in Table 2.1 (Hennekens and Buring, 1987).

Table 2.1 Epidemiological terms

Term	Definition
Incidence rate	Number of new cases of disease that develop in a population at risk during a specified time interval (a cumulative incidence rate may also be given).
Prevalence rate	Proportion of individuals in a population who have a disease at a specific instant (point prevalence) or over a particular time period (period prevalence).
Mortality rate	Incidence of death from a particular disease in a population during a given time period.
Case fatality rate	Number of deaths from a disease divided by all cases of that disease (i.e. the case fatality rate is a function of disease severity).

The majority of data relating to the epidemiology of TBI has been collected in clinical rather than population based settings. Although this information is useful to the clinician, a broader and more accurate assessment of the occurrence, characteristics and outcome of TBI in the population is required (Kraus and Sorenson, 1994). Before the major epidemiological studies of TBI are reviewed, case ascertainment, enumeration of the population at risk and the time interval of the study are briefly discussed.

Case ascertainment

Precise case definition is vital to ensure inclusion of a concise group of patients with clear exclusion criteria. Rigorous methods must be employed so that all possible cases are identified using hospital admission and discharge data, procurator fiscal reports and death certificates. All hospitals in the study area must be included in the data collection process and deaths prior to hospital admission should also be documented for the accurate calculation of incidence. In most countries including the UK, A&E attenders are not

routinely included in the hospital statistics making this group more difficult to study (Field, 1976). Even for those admitted to hospital with a TBI, it can be difficult to ensure that all cases are identified. For example, if the patient has sustained multiple injuries care may primarily be given by orthopaedic or general surgeons, rather than neurosurgeons, and the TBI may not be documented in the discharge summary or death certificate (Kraus and McArthur, 1996). For studies attempting to quantify the number of TBI cases in the population, the problem of identifying those who do not seek medical attention needs to be addressed (Field, 1976). It must be assumed that the incidence rates for TBI commonly quoted, underestimate the overall size of the problem.

Enumeration of the population at risk

The population at risk must be properly enumerated as this forms the denominator in the calculation of incidence. Census information is commonly used for this purpose and the inclusion of non-residents, such as holiday makers and members of the armed forces, varies between studies (Kraus et al. 1984). Some argue that their inclusion is justified as they would be balanced by injuries sustained by local residents elsewhere in the same period.

Defined time interval

The time interval of the study must be stated and needs to be of sufficient length to allow accurate estimation of the incidence.

Epidemiological studies

The major epidemiological TBI studies will now be reviewed with regard to these considerations and their results compared. It should be noted that the term 'head injury' rather than TBI is used in this section to be consistent with the terminology used in the referenced papers. The epidemiological statistics from these studies are presented in Table 2.2.

Table 2.2 Epidemiological studies of TBI

Study	Incidence rate†	Mortality rate†	Case fatality rate	Pre admission deaths
SHIMS (1977)	313	10.5	3.2%	51%
Kalsbeek et al. (1980)	200	-	-	-
Jennett & MacMillan (1981)	270	9.5	3.7%	57%
Klauber et al. (1981)	295	22.3	7.5%	65%
Kraus et al. (1984)	180	30	17%	11.5%
Tiret et al. (1990)	281	22	7.8%	55%

† per 100,000

United Kingdom

A survey undertaken by a Glasgow based team, The Scottish Head Injury Management Study (SHIMS) (1977), aimed to collect comprehensive data relating to head injury distribution and management. Cases were ascertained retrospectively from A&E, primary surgical wards and neurosurgical units based in Glasgow, Aberdeen and Dundee over a one year period (1974). Data from Edinburgh was not included because of a different admission policy where all patients were managed in the acute neurosurgical unit regardless of severity.

Jennett and MacMillan (1981) used routinely published statistics and specially conducted surveys to estimate the mortality, hospital admission and A&E attendance rates following head injury in Scotland. They used ICD-8 codes to identify deaths and hospital admissions due to head injury over a two year period (1974-5), and included those who had only sustained a skull fracture. The population at risk was not defined.

United States of America

National Head and Spinal Cord Injury Survey

A National Head and Spinal Cord Injury Survey was undertaken during 1974 in the US (Kalsbeek et al. 1980). Head trauma was defined as 'physical injury to living tissue caused by an external force' and the survey was based on a national sample of admissions to hospital following a traumatic incident. Deaths prior to hospitalisation were excluded. Cases were identified from ICD-8 codes and review of the discharge summary. The authors acknowledged that case ascertainment may have been incomplete or inconsistent because of the methods used.

San Diego County, California

A one year prospective study took place in San Diego County in 1976 (Klauber et al. 1981). The diagnosis of head injury was based on ICD-8 coding, including those with a skull fracture but excluding soft tissue and gunshot injuries. Both admissions and immediate deaths were included. The sources used to ascertain cases were hospital discharge databases (although it is unclear whether all hospital in the area were included), an emergency room survey of 1000 patients, coroners reports of fatal head injuries and mortality data. The population at risk was defined as residents and non-residents of San Diego County.

A second prospective study looked at the number of new cases of TBI during 1981 in San Diego County (Kraus et al. 1984). Head injury was defined as 'physical damage to, or functional impairment of, the cranial contents from acute mechanical energy'. Both open and closed injuries, with a physician diagnosed brain injury leading to immediate death or admission to hospital, were included. Those with skull or facial fractures or soft tissue injuries, without brain injury, were excluded. Cases were identified from A&E and hospital admission records from all hospitals in the area, death certificates, a review of coroners cases and a survey of nursing homes and extended care facilities. The population at risk was determined from census data and non-residents were excluded.

France

In 1986, a study was undertaken to determine the frequency of head trauma in a defined region of France over a one year period (Tiret et al. 1990). Head trauma was defined as contusions, lacerations, skull fractures, brain injuries and/or loss of consciousness but those with facial injuries without loss of consciousness were excluded. Both admissions and deaths prior to admission were included. Representative sampling of hospital admissions was undertaken, and although the method of case identification is not clearly stated it appears to have been based upon questionnaires completed for all admissions. Deaths were identified from a review of death certificates. The population at risk was determined from census data and included residents and non-residents.

Comparison between study designs and methodology

The literature review has shown that the majority of epidemiological studies took place in the 1970's and 1980's. Accurate epidemiological data is difficult to find and even more difficult to compare between studies or countries, because of varying definitions of brain injury, methods of case ascertainment and denominators. For instance, the inclusion or exclusion of deaths prior to hospitalisation has a considerable effect on the statistics as illustrated by the prospective study by Klauber et al. (1981). This study included all admissions to hospital, as well as pre-admission deaths, and reported a case fatality rate of 7.5%. Sixty five percent of the deaths occurred prior to hospitalisation and if these cases had been excluded, the case fatality rate would drop to only 3%.

Summary of incidence, mortality and case fatality rates

Epidemiological data vary between centres and over time. The estimated incidence of TBI in the UK is approximately 200-300 per 100,000 population, with the rate for England and Wales 270 per 100,000 population (range 210-360 per 100,000) but 313 per 100,000 population for Scotland (range 306-404 per 100,000) (Jennett and MacMillan, 1981). In the US, the estimated incidence is believed to be considerably lower than many other countries (175-200 per 100,000 population) and this is likely to relate to their hospital admission policies (Kraus and McArthur, 1996). Recent figures indicate that UK admission rates are dropping with the introduction of more rigorous admission criteria (Miller et al. 1992). The majority of hospitalised cases of TBI, estimated at around 80%, are classified as mild injuries, 5-10% are severe and the remainder are moderate (Sorenson and Kraus, 1991; Miller et al. 1992; Jennett, 1996). In the UK, 60-70% of all hospitalised cases are discharged within 48 hours (Jennett, 1996).

The documented mortality rate varies throughout the world depending partly on the definition of TBI and the inclusion or exclusion of pre-admission deaths (Jennett, 1996; Kraus and McArthur, 1996). In the UK, the mortality rate from TBI has been falling over the last 20-30 years and is currently estimated at around seven per 100,000 population (Jennett and MacMillan, 1981; Jennett, 1996). In the US, the rate is approximately 19 per 100,000 population (Sosin et al. 1995) and this is also thought to have declined in recent years (Sosin et al. 1989). A similar rate of 22 per 100,000 has been quoted for France (Tiret et al. 1990). Case fatality rates also vary greatly, from 3.2% for Scotland (Jennett and MacMillan, 1981) to 17% in some US studies (Kraus et al. 1984). It is difficult to compare the case fatality rates however as most studies do not state the time period in which a death

would be ascribed to the TBI. Survival analyses relating to TBI are difficult to find in the literature.

Prevalence rates

Very few prevalence studies of TBI exist. In Canada, the Health and Activity Limitation Survey (HALS) (Moscato et al. 1994) found a prevalence rate of self reported disability following TBI of 62.3 per 100,000 adults, with the highest rate in the 35-64 year olds. When broken down by sex, the rate was 81.3 per 100,000 for males and 44.2 per 100,000 for females. The most common disability was impaired mobility and agility. Disability had lasted for more than five years in 65% of adults and for more than 10 years in 45% emphasising the chronic nature of TBI. In Strathclyde, Bryden (1989) estimated a community prevalence of self reported disability following head injury of approximately 100 per 100,000 population.

The US National Head and Spinal Injury Survey (Kalsbeek et al. 1980) reported a prevalence rate for head injury of 439 per 100,000 population. However, it should be emphasised that this survey is not comparable with the Canadian and Scottish studies just described. This US survey included children, was hospital rather than community based, employed a different case ascertainment method and related to the occurrence of head injury rather than the resulting disability.

AETIOLOGY OF TRAUMATIC BRAIN INJURY

The most frequent cause of fatal and non-fatal TBIs world-wide, are road traffic accidents (RTAs), followed by falls then personal assaults. However as the cause of injury varies greatly between centres, and is related to age and severity, it is difficult to estimate the percentage of TBIs due to RTAs, falls or assaults (Jennett, 1996; Kraus and McArthur, 1996). In Scotland, for 15-64 year olds the figures were 24% RTAs, 27% falls and 32% assaults but for those over 64 years they were 23%, 40% and 3% respectively (Jennett, 1996).

Cause of injury

Road traffic accidents

The majority of RTAs involve vehicle occupants (Kraus et al. 1984; Brookes et al. 1990) with smaller numbers involving pedestrians, motorcyclists and bicyclists. Rates tend to be highest in the young, male population with a peak in 15-24 year olds (Kraus et al. 1984). The number of road deaths appears to be decreasing in many developed countries and this may be partly explained by the introduction of the seatbelt laws (Miller et al. 1992).

Falls

Falls are a particularly important cause of injury in the very young and the elderly, and are commonly associated with alcohol in adults (Kraus et al. 1984; Jennett, 1996). There is a tendency for falls to be under-reported and it is thought that a proportion of assaults are reported as falls (Jennett, 1996).

Assaults

Assault rates vary greatly between centres with more reported in economically depressed and densely populated areas (Jennett, 1996). They are associated with the young, male population (Kraus et al. 1984).

Factors associated with Traumatic Brain Injury

Some of the factors associated with TBI are age, sex, socio-economic status and alcohol.

Age

The age group at greatest risk of sustaining a TBI are young adults (15-24 year olds). Those in their middle years are at least risk and a smaller peak after the age of 60 years is

commonly reported (Kraus and McArthur, 1996). These differences can probably be explained in terms of exposure rates to RTAs and falls.

Sex

Males are generally thought to be at greater risk of TBI than females and this may reflect differences in exposure to occupational hazards or risk taking. Population based incidence rate ratios between the sexes vary from 2.0-2.8:1.0 (Kraus and McArthur, 1996). Males also tend to sustain more severe injuries and have a higher mortality rate (Klauber et al. 1981; Kraus et al. 1984).

Socio-economic status

In general, it is thought that lower socio-economic status is associated with a higher rate of TBI and it has been suggested that this may relate to occupational exposure, older vehicles, violence and poor housing (Jennett, 1996; Kraus and McArthur, 1996).

Alcohol

The consumption of alcohol is often assumed to be a predisposing factor to traumatic injury. Galbraith et al. (1976) reported that alcohol was present in 62% of male and 27% of female TBI admissions. The alcohol level was found to be higher in men and most strongly associated with assaults and falls. Two Scottish A&E studies found that around a quarter of adults had consumed alcohol recently and again this was associated with assaults and falls (Strang et al. 1978; Brookes et al. 1990). Strang et al. (1978) found that recent alcohol consumption was more common in men and in those admitted to hospital, but it is unclear whether this related to more severe injury or because of difficulty in assessment of the conscious level. Galbraith et al. (1976) concluded that although a depressed conscious level is often attributed to excess alcohol, it is important to know the level of blood alcohol at which alteration in conscious level is likely and they estimated this to be 200mg/100ml.

2.2 OUTCOME FOLLOWING TRAUMATIC BRAIN INJURY

INTRODUCTION TO OUTCOMES ASSESSMENT

> 'Outcomes in rehabilitation are in a sense like paintings. They depict aspects of reality that can be portrayed in many ways, viewed from different perspectives, and understood from several frames of reference.'
>
> (Diller and Ben Yishay, 1987)

This quotation provides a useful starting point when considering outcome following TBI as it emphasises the different viewpoints of those involved. Outcome was initially expressed in terms of survival, however as many TBIs are not fatal and the majority of deaths occur soon after injury, survival itself is not a sufficient method of expressing outcome, particularly as time progresses. The consequences of TBI are complex and varied and the sequelae experienced may be difficult to relate to the antecedent pathology. Recovery from injury may not be complete and assessment must encompass a wide range of possible outcomes.

> 'success should be measured less by survival and more by the quality of survival'
>
> (Jennett and Bond, 1975)

> '.. the ultimate goal is not cure but enhanced function, that is, the ability to function as independently as possible within a specific set of activities. Consequently, outcome measures must extend well beyond the performance of a specific organ and the mere absence of pathology. Simply put, medical rehabilitation is a more holistic discipline. As such, its measurement tools must necessarily address a wider spectrum of activity than most specialities .... outcome measures have always lagged behind clinical practice, social norms, and the expectations of persons with disabilities'
>
> (DeJong, 1987)

Why assess

The increased emphasis on assessment and outcomes throughout medicine has been driven by a number of factors including the need to increase understanding of the effectiveness of various interventions and explore differences in outcome between centres (Epstein, 1990). In addition, greater knowledge of outcome may assist decision making and aid the development of standards to guide physicians and administrators in optimising resources. Within the field of rehabilitation following TBI, outcomes assessment is important in predicting eventual outcome for groups, or if possible, individuals.

How and when to assess outcome

Properties of an outcome measure

There are certain properties such as validity, reliability and responsiveness which should be established before an outcome measure is accepted for widespread use. Validity refers to the ability of the assessment tool to measure what it is supposed to and achieve the purpose required. It includes construct validity, the degree to which results obtained concur with the results predicted from the underlying theoretical model; criterion validity, the testing of a measure against some outside criterion or gold standard; and content validity where component items should not only relate to the construct being measured, but also cover all aspects of that construct (Wade, 1992a).

Reliability is the extent to which two observers or two observations agree (Wade, 1992a). A measure is said to be reliable when it consistently produces the same results, particularly when assessing the same subjects over time (Bowling, 1997a). Variations may occur in the patient's state, between observers (inter-rater) or within the same observer (intra-rater). Measures of reliability should indicate how closely the two obtained results relate to each other and whether bias has affected the readings. Internal consistency should also be assessed by testing correlations between scale items, within scale domains or between items and the total score. Cronbach's coefficient α, used to determine internal consistency, is based on the average correlation among the items and the number of items in the instrument (Cronbach, 1951). Responsiveness is less commonly reported, but refers to the ability to detect minimal clinically important differences and is vital in a measure used for serial assessments (Guyatt et al. 1987).

Generic and disease-specific outcome measures

Choosing the appropriate outcome tool may be assisted by thinking in terms of generic or disease-specific measures (Patrick and Deyo, 1989). Generic health status measures tend to be designed to summarise a range of health concepts and claim to be broadly applicable across different diseases, methods of management, demographic and cultural groups. Disease specific measures are developed to assess particular diagnostic or patient groups and are often used to assess and quantify change over time. Such measures are very common and are available for many different conditions (Patrick and Deyo, 1989). A combination of both generic and disease-specific measures may be most suitable for the subject under study.

With regard to TBI, there is a recognised need for serial examination of functional status to guide clinical practice, scientific evaluation of therapeutic interventions and assessment of economic consequences following rehabilitation (Ditunno, 1992; Frattali, 1993; Johnston and Hall, 1994). There has been a proliferation of outcome measures which initially focused on physical difficulties but more recently have taken account of the psychosocial dimensions which are particularly important to this population (Hall et al. 1993; Pentland and McPherson, 1994). The majority of measures such as the Functional Independence Measure (FIM) (Keith et al. 1987) and the Disability Rating Scale (DRS) (Rappaport et al. 1982) have originated in the US. Very few measures assess the patient from the time of insult to several years post-injury but one which attempts to do this, the European Head Injury Evaluation Chart, is the focus of Chapter Three in this thesis.

Timing of assessment

An issue related to the development of outcome measures concerns the timing of assessment. Do we know, or can we predict, when is recovery complete? Does improvement continue for an indefinite period of time, or does there come a point when further progress is unlikely? It is thought by a number of authors that most improvement occurs in the first six months after TBI (Jennett and Bond, 1975; Teasdale and Jennett, 1976) however others have argued that progress may be evident for several years (Thomsen, 1984). When to assess outcome will depend upon the focus of the research although the majority of studies have focused on the first two years post-injury, with only a handful of studies reviewing patients beyond this stage. This area will be further explored in this thesis.

International Classification of Impairments, Disabilities and Handicaps

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) is a manual used to classify the outcome of diseases and disorders. It was developed by the World Health Organisation in order to assist a better understanding of disabling illness (World Health Organisation, 1980). It divides the consequences of diseases and disorders into three levels (Table 2.3). For neurological illness, Wade (1993) has suggested that as time progresses, impairment and disability become less important whilst handicap has the greatest impact on the individual's life.

Table 2.3 Abbreviated ICIDH classification

Impairment	Abnormality or loss of psychological, physiological or anatomical structure or function
Disability	Any restriction or lack (resulting from impairment) of ability to perform an activity within the range considered normal for a human being
Handicap	Disadvantage for a given individual, resulting from impairment or disability that limits or prevents fulfilment of a role that is normal (depending on age, sex, social and cultural factors)

What to assess

Depending on the type, extent and location of the damage, TBI can affect many areas of a patient's life making the process of assessment very complex from a clinical or research perspective. The relative importance of specific areas will differ for the patient, family and professional, and will vary over time. The use of a global outcome measure in conjunction with more specific measures may be appropriate.

ASSESSMENT OF THE LONG TERM CONSEQUENCES OF TRAUMATIC BRAIN INJURY

> '..blunt head trauma causes diffuse neuronal damage and physical, cognitive and psychosocial impairment, including behavioural, emotional and social disturbances'
>
> (Thomsen, 1987)

The above quote by Thomsen (1987), one of the main researchers in this field, reflects the breadth of sequelae associated with severe TBI and hence the difficulties facing researchers. Although there is a wealth of published data on aspects of TBI, relatively few studies have focused on long term outcome. This is surprising as it is believed that, particularly following severe injury, disabilities may persist for the rest of the patient's life (Thomsen, 1984). It is therefore difficult to predict the subsequent prevalence of disability and handicap and how this may vary over time, but given the incidence of TBI the extent of the problem in the community may be considerable. Prior to the 1970's outcome following TBI tended to focus on indicators such as return to work and physical status. However more recently there has been increased attention on psychosocial recovery, emotional and behavioural problems although areas such as quality of life have rarely been studied in TBI.

Studies of long term outcome following Traumatic Brain Injury

Table 2.4 provides details of the main research studies which have focused on the long term consequences of TBI.

Table 2.4 Long term follow up studies of TBI patients

No†	Location	Assessment	n	Severity	Main areas of assessment	Informant
1.	UK	2-7 yrs	34	Severe	Social adjustment	Relative
2.	Denmark	4.5 mths, 2.5 & 10-15 yrs	40	Severe	Physical, psychiatric and psychosocial sequelae, cognition and work capacity	Patient & relative
3.	Canada	2-4 yrs	78	Mixed	Perceived health status and neurobehavioural status	Patient & relative
4.	UK	5-7 yrs	134	Severe	Subjective, physical, cognitive, emotional and behavioural status	Patient & relative
5.	US	1-6 yrs	142	Severe	Activities of daily living, mobility, cognition, social skills, emotion, behaviour and work capacity	Relative
6.	US	5-10 yrs	55	Severe	Physical and mental impairment, mood, work and living situation	Patient or relative
7.	Australia	2 & 5 yrs	103	Mixed	Activities of daily living, mobility, leisure, employment, cognition and behaviour	Patient & relative
8.	France	5 yrs	407	Mixed	Functional status and behavioural outcome	Patient & relative

† 1. Weddell et al. (1980) & Oddy et al. (1985); 2. Thomsen (1984); 3. Klonoff et al. (1986); 4. Brooks et al. (1987); 5. Jacobs (1988); 6. Rappaport et al. (1989); 7. Ponsford et al.(1995) & Olver et al. (1996); 8. Masson et al. (1997)

Psychosocial, emotional and behavioural problems

> 'the most severe permanent effects are the psychosocial problems and their consequences for the life of the patient and his relatives'
>
> (Thomsen, 1987)

Continuing psychosocial problems tend to be a major concern for relatives several years after injury. However, measurement of psychosocial recovery is difficult because of the lack of objective measures available. Two and a half years post-injury, Thomsen (1984) found that around 80% of families reported changes in personality such as childishness, aspontaneity, emotional lability and irritability to be a severe problem, and this continued in 65% of her sample at 10-15 years. Similar results were found by Brooks et al. (1987) with relatives indicating that personality changes, anger, irritability and impatience were a problem in around three-quarters of patients two to seven years after injury. A fifth of patients were also found to be aggressive and sexually disinhibited. However, it must be highlighted that both Thomsen and Brooks studied severely or very severely injured populations.

Loneliness was found to be of major concern to patients (Thomsen, 1987; Ponsford et al. 1995). Thomsen (1984) found that lack of social contact was the greatest problem for 60% of patients at 2.5 years and for 68% at 10-15 years. Ponsford et al. (1995) found that half of her sample felt socially isolated and Olver et al. (1996), who followed up a subgroup of this sample at five years, found that patients became more aware of social isolation over time. Thomsen (1984) felt that social isolation arose from a lack of opportunity to make social contacts but Weddell et al. (1980) suggested that although the frequency of social contact had diminished and the nature of relationships had changed, this was not appear directly related to either absence from work or physical disability. Weddell et al. (1980) also reported that there had been a great change in patients' social life and they were more likely than controls to be involved in social activities with their families.

It is generally believed that patients report fewer behavioural problems than their relatives (Thomsen, 1984; Brooks et al. 1987). However Ponsford et al. (1995), whilst acknowledging the criticism of self report and lack of awareness in this population, found that patients indicated similar levels of problems to those reporting relative's views (Weddell et al. 1980; Jacobs, 1988). Ponsford et al. (1995) discovered that nearly three quarters of patients reported memory problems, and two thirds reported problems with

slowness of thinking, concentration, word finding and irritability. Tiredness and fatigue was found in around 70% by Ponsford et al. (1995) and Brooks et al. (1987).

Employment

Return to work was, and to a certain extent still is, one of the major measures of outcome and has been used as the traditional indicator of social recovery (Humphrey and Oddy, 1980). Because of the young age of many victims of TBI, return to work tends to be of particular importance to patients. Rappaport et al. (1989) found that of those in the labour force, unemployment was the major concern for 17% of the population. He reported that unemployment rose from 0% at the time of injury to 61% at follow up. Similarly Brooks et al. (1987) found a rise in unemployment from 13% pre-injury to 63% at seven years post-injury, with no evidence of improvement in employment status between two and five years after injury. In the study by Ponsford et al. (1995), the rate of unemployment was considerable pre-injury (24%) and this figure more than doubled after two years. The five year follow up study of this sample found that there had been a decline in employment rates since the two year assessment (Olver et al. 1996). Thomsen (1984) reported that less than a quarter of her sample had been employed in full or part-time work during the period of follow up, and Weddell et al. (1980) found that just over a third had returned to work either in their previous role or at a lower level.

Following a literature review, Humphrey and Oddy (1980) concluded that as well as injury severity, occupational resettlement was influenced by age, pre and post-injury personality and occupational level. It appeared to be related to a measure of global outcome as well as disturbance of cognition, memory and personality (Levin et al. 1979a; Weddell et al. 1980; Evans, 1989). With the exception of epilepsy, residual neurological deficits are not important determinants in return to work (Richardson, 1990a).

Although useful as part of an overall assessment, there are limitations to using return to work as a measure of outcome. For example, it can only be applied to those who were previously employed; it depends on the previous type and level of job, as well as employer and it is difficult to apply to certain groups, such as children or the elderly (Baddeley et al. 1980).

Physical problems and level of dependence

Physical impairments tend to be a frequent and conspicuous problem following TBI and are a common focus for both patient and relative particularly in the early stages (Richardson, 1990a). In a very severely injured sample, Thomsen (1984) found that all patients had motor impairments 4.5 months post-injury, and a third had severe deficit at 2.5 and 10-15 years. As time progresses however, physical problems are less frequently reported as a major cause of difficulty, but why this change in attitude occurs is unclear. It may be that the patient and family is better able to accept and cope with an obvious, visible disability or that other problems become more prominent or distressing and may be less amenable to modification.

Activities of daily living (ADL) refer to the everyday tasks such as washing, dressing, eating, shopping, and managing finances and reflect an individual's level of dependence on others. Although physical deficits may restrict a person from performing self care and other ADL, cognitive or behavioural problems may also be a factor. Thomsen (1984) found that levels of dependence in self care decreased from 50% at 2.5 years, to 30% at 10-15 years. Rappaport et al. (1989) reported that around a fifth of patients felt their physical problems and dependence on others was a major problem, and the percentage living in supported accommodation rose from 0 to 24% after injury. Ponsford et al. (1995) found that although the majority of subjects were independent in personal and domestic ADL at two years post-injury, about a third still required supervision or assistance with community activities such as shopping. At the five year follow up of this sample, there had been a significant improvement in independence in domestic and community ADL (Olver et al. 1996).

Cognitive deficits

It is widely recognised that an individual's cognitive ability (such as memory, information processing, attention, visuo-spatial ability) may be affected by TBI. In general, increasing injury severity is associated with more persistent, global impairment (Jennett et al. 1981). Testing for cognitive deficit is primarily the domain of the neuropsychologist. However basic assessment may be undertaken by other professionals and information from the patient and family may elicit the effect of any impairment on daily life. Memory deficits have been reported in around 75% of patients in several studies (Thomsen, 1984; Brooks et al. 1987; Ponsford et al. 1995). Thomsen (1984) found that the frequency of memory problems varied greatly depending upon the source of information with much higher rates detected by clinical observation and assessment than reported by the patient or relative. Poor

concentration and slowness are also commonly reported (Thomsen, 1984; Brooks et al. 1987; Ponsford et al. 1995).

Language and communication problems

Problems relating to language function and communication are a recognised complication of TBI, and the main types of deficit are dysarthria and dysphasia. Dysarthria relates to disorders of articulation, and dysphasia may be expressive or receptive in nature (Clarke, 1987). Sub-clinical disturbances of language function and communication are much more common than classical aphasia (Richardson, 1990a). Thomsen (1984) found that 40% of individuals were dysphasic and/or dysarthric at 2.5 years and although the percentage with dysphasia dropped to 10% at 10-15 years, the frequency of dysarthria remained constant. Over two-thirds of Ponsford's sample (1995) reported word finding difficulties and Brooks et al. (1987) found that communication deficits were an important factor in determining return to work.

Change over time

It is often said that improvement only takes place in the initial months after injury (Jennett and Bond, 1975; Teasdale and Jennett, 1976) and although this is when the most rapid changes are seen, gradual improvement may continue for several years (Thomsen, 1984; Rappaport et al. 1989; Olver et al. 1996). Thomsen (1984) found that whilst there was a high frequency of disability and handicap in her population at all follow up assessments, some improvement in the longer term was evident. Relatives reported a gradual reduction in behavioural problems over the first five to six years although clearly many still had ongoing difficulties. Olver et al. (1996) reported that there were significant functional gains in domestic and community ADL between two and five years.

Unfortunately, some areas may actually worsen over time (McKinlay et al. 1981; Thomsen, 1984; Brooks et al. 1987). Thomsen (1984) found that tiredness, lack of interest and distress were found to increase significantly between the follow up visits. It has been suggested by Brooks et al. (1987) that relative's reports of increasing levels of disturbance are unlikely to indicate brain damage per se, but may reflect the patient's frustration at the changes and restrictions in his life or lower levels of tolerance by relatives. Patient reports of increased cognitive, emotional and behavioural problems, social isolation and dependency on others over time have also been documented (Olver et al. 1996). However it is recognised that this may reflect an improvement in the patient's self awareness rather than

an actual change. Increasing levels of psychological problems over time have also been described in other groups who have survived severe, life-threatening events, for example burns patients (White, 1982).

2.3 SOURCE OF INFORMATION AND METHOD OF DATA COLLECTION

The source of information and method of data collection is of prime importance in any study. In many fields, there appears to be an increasing reliance on postal or telephone data collection with the emergence of self report descriptive health outcome measures such as the Short Form 36 (SF-36) (Ware and Sherbourne, 1992).

SOURCE OF INFORMATION

A number of individuals may be used to assess the consequences of TBI - the professional involved in the patient's care, a relative or carer, or the patient. The advantages and disadvantages of gathering information from each of these sources are discussed below.

Rating by a professional

Some types of information are best collected by a professional, for example when measurements require particular techniques or tools, such as the assessment of muscle power, spasticity or cognitive ability. For more subjective areas such as emotional or behavioural status, the professional has the ability to provide an unbiased account. However he will only be able to observe the patient in a limited range of settings for short periods of time and has little, if any, knowledge of the patient's pre-morbid functioning.

Rating by a relative/carer

A relative or carer is regarded as a useful informant by many researchers, and some argue that the relative is most able to give an accurate description of the patient's problems (McKinlay and Brooks, 1984; Brooks et al. 1987). A relative will have known the patient prior to the accident and can therefore make comparisons between pre and post-injury status and is usually able to observe the patient over extended periods of time in many different situations.

There are important issues to be aware of when relying on information provided by relatives. The sudden burden of having to care for a previously independent adult is likely to impose great stress on the relative, and their close personal involvement may influence their ability to give an objective rating. The relative's ability to cope, and the degree to which their need for additional support is met, will vary between individuals and over time. Some relatives may feel that the behaviour of the patient is a reflection upon themselves and will not admit to experiencing any difficulties. Others may feel that they are not being adequately assisted by the available services and this may be reflected in their responses. Weddell et al. (1980) conclude that the majority of relatives give an honest and accurate picture of the patient's difficulties, although they do acknowledge that some relatives tend to be over-protective.

Self-rating by patient

The other source of information is the patient himself. Ellwood (1988) believes that one of the most important developments over recent years is the increased emphasis on the patient's point of view and his perception of outcomes. By asking the patient, it is possible to reflect his opinion on the problems faced and also to collect information on areas that are not easily observed. In addition, the patient may be able to provide further information on their pre-injury status.

It is important to be aware of the limitations of using the patient to provide information, particularly as the injury itself may have affected the patient's memory and self awareness. Some researchers feel that a brain injured individual may be unable to provide a valid and reliable estimate of daily functioning, cognitive, emotional or behavioural status because of memory problems and poor insight (Weddell et al. 1980; McKinlay et al. 1981; McKinlay and Brooks, 1984). Alternatively, others have concluded that in the majority of cases, patients opinions are valid and that they tend to report similar, if not higher, levels of disability than their relatives (Oddy et al. 1978; Rappaport et al. 1989; Ponsford et al. 1995).

Finally, which source of information is used to collect data concerning the TBI population depends on several factors including the severity of injury, time since injury and the type of information required. It is important to be aware of the effect of the injury on the patient's ability to accurately assess and recall his functioning. Equally the stresses and pressures faced by the relative may bias his account of the patient, and even in a healthy population

there are obvious difficulties when asking one individual to assess another's feelings and beliefs. Levin et al. (1987) suggest that self-administered measures are

> 'primarily useful to evaluate long term outcome of closed head injury rather than during the early post-traumatic period when severely injured patients are frequently unable to complete lengthy questionnaires because of confusion, attentional deficit, restlessness and agitation'

Although using the most accurate informant is important, there will be times, as noted by Tyerman and Humphrey (1984), when the patient's opinion may be more relevant even though this may not agree with the view of others.

METHOD OF DATA COLLECTION

Not only is it important *who* the data is collected from, but also the *method* by which it is collected. Although traditionally data has been collected by face-to-face interview, in many areas of research there has been increasing reliance on postal or telephone surveys. These methods have the advantage of being quicker and cheaper (O'Toole et al. 1986; McHorney et al. 1994a) and may allow a greater number of respondents to be reached. In addition, Ware (1995) suggests that a postal survey has the advantages of 'greater convenience and privacy, and satisfactory levels of reliability and validity'. However, Maas et al. (1983) stressed the importance of face-to-face interviews for obtaining reliable information and Brooks (1989) argues this method will provide the highest quality of data. However, sufficient resources may not always be available to undertake face-to-face interviews and the alternatives of postal and telephone survey are discussed below.

Postal surveys

Postal surveys have been used very infrequently in the TBI population. Motor, visual and cognitive deficits can make the completion of paper questionnaires difficult or impossible without assistance, therefore limiting the population that are able to respond. If assistance is required from another individual, for example a relative or friend, it is important that this is documented and its influence on assessment is taken into account. As already noted, a relative may have different views on the patient's functional status and well being, and therefore the responses may reflect the relative's view rather than that of the patient. In a postal survey it is clearly very difficult for the researcher to have control over the type and degree of help that the subject may receive, although these disadvantages must be weighed against the advantages of reduced costs and larger population size.

Two studies have reported the use of postal surveys in a TBI population (Sunderland et al. 1984; Bohnen et al. 1994). Sunderland et al. (1984), studied memory failures in the severely injured one and a half to six years post-injury, and Bohnen et al. (1994) compared the frequency of late post-concussive symptoms between mild TBI patients and controls one to five years after injury. They reported response rates of 70% and 68% respectively and although the former study did report problems with recall this was felt to be due to the type of assessment being undertaken. Therefore as time since injury increases, particularly with the less severely injured, the use of postal surveys may be a valid means of collecting information and requires further investigation.

Telephone interviews

Telephone surveys are increasingly being used in research although are rarely documented in studies of the TBI population. Severe cognitive and/or communication problems may exclude some individuals. Rappaport et al. (1989) studied outcome up to ten years post-injury using telephone interviews as the primary means of assessing impairment, disability and handicap. In around half the sample a significant other rather than the patient was used as the main informant. Brooks (1989) suggests that a telephone survey 'sacrifices quality of data for quantity and speed'. It may also limit the format of questions used although this can be partially overcome by sending written material to the subject allowing more complex areas to be addressed. Telephone interviews are thought to reduce non-response bias and missing data compared with postal surveys (McHorney et al. 1994a), but the choice of data collection method must be determined by the focus of the study.

2.4 SUMMARY

This chapter has provided details of the epidemiology of TBI. Much of the published research has been taken from clinical, rather than population based, settings. Although this information is valuable for those working in the clinical field, in order to obtain an overview of the occurrence, characteristics and outcome of TBI in the population, a broader perspective is required. Following a review of the major epidemiological studies, it is clear that the definition of a 'case' varies greatly, the collection of data is often incomplete, and the population at risk is not carefully enumerated. These inconsistencies make comparison between studies and countries very difficult, if not impossible. The aetiology of TBI has been briefly discussed and although this varies between countries and over age ranges, the most common cause world-wide is the road traffic accident. At the extremes of age, falls are important and may be associated with alcohol.

The second half of this chapter has focused on long term outcome following TBI. General issues surrounding outcome were introduced and a review of current research of long term outcome of TBI presented. The final section has provided a discussion of possible information sources and highlighted the advantages and disadvantages of each. The implications for data collection and analysis are discussed with particular reference to the TBI population. Interviews are the method of data collection in Chapters Three, Four and Five and a postal survey is employed in Chapters Six and Seven.

Chapter Three
The European Head Injury Evaluation Chart

3.1 INTRODUCTION

In 1990, the European Brain Injury Society (EBIS) developed the European Head Injury Evaluation Chart (EHIEC) as both a clinical and research tool for assessing outcome after head injury. Clinically, it was designed to provide information for routine use in rehabilitation practice. Scientifically, it was proposed that it would enhance the knowledge of the natural history of head injury recovery and allow the evaluation of the relative effectiveness of specific rehabilitation programmes (Truelle et al. 1990; Truelle and Robert-Pariset, 1990). A third claim was that it would afford detailed information for medicolegal purposes. It was also described as simple enough to be used by any rehabilitation professional and to be applicable from initial hospitalisation to several years post-injury (Truelle and Robert-Pariset, 1990). The EHIEC was based on the ICIDH model which was previously summarised in Section 2.2.

This chapter presents a descriptive study which aimed to determine the utility of the EHIEC as a comprehensive outcome measure when used to evaluate TBI patients at discharge from in-patient rehabilitation, and 15 months later. Ethical approval for the study was obtained by the rehabilitation unit.

3.2 STUDY METHODOLOGY

STUDY POPULATION

The sample comprised 47 patients, discharged consecutively, from the Scottish Brain Injury Rehabilitation Service, Astley Ainslie Hospital (AAH), Edinburgh during 1994. The AAH is a rehabilitation hospital serving South East Scotland. The majority of patients had been admitted to the unit as transfers from acute neurosurgical or orthopaedic units in Scotland with the remainder being transferred from hospitals abroad. All had undergone a period of multidisciplinary in-patient rehabilitation. All 47 patients were assessed at the time of discharge from the unit and a subgroup of 35 were re-assessed at 15 months post-injury.

OUTCOME MEASURES

European Head Injury Evaluation Chart

The EHIEC (Appendix A) comprises 175 items of information divided into two parts: Section One and Section Two. It is recommended that Section One (Items 1-52) is completed either during first hospitalisation, or at a later date from the patient history and medical records. It details demographic information, the pre-traumatic situation, circumstances of the accident, injuries sustained, initial complications and their management. Section Two (Items 53-175) is designed for completion at the initial examination and at regular intervals thereafter by interviews with the patient and primary carer. It covers problems pertinent to impairment, disability and handicap including the patient's physical, intellectual, affective and behavioural state, as well as activities of daily living (ADL), family, social and vocational issues. All information presented is as detailed in the EHIEC unless otherwise stated.

Functional Assessment Measure

In addition to the EHIEC, patients were also assessed on the Functional Assessment Measure. This is a 30 item measurement tool derived from the 18 item Functional Independence Measure (FIM) by the addition of 12 items of particular relevance to brain injury (Keith et al. 1987; Ditunno, 1992; Hall et al. 1993). This explains the accepted abbreviation of FIM+FAM. The FIM+FAM assesses ADL, cognitive, communicative and psychosocial function (Table 3.1) and all items are scored on a seven point ordinal scale (Table 3.2). The psychometric properties of the FIM+FAM are further described in Chapter Four, but there is increasing literature to support its validity and reliability (Frattali, 1993; McPherson et al. 1996; McPherson et al. 1997). The FIM+FAM was recorded routinely in the unit at the time of discharge and at the 15 month review by the author.

Table 3.1 Functional Assessment Measure dimensions

Motor items	Cognitive items
Self Care	**Communication**
Swallowing	Comprehension
Feeding	Expression
Grooming	Reading
Bathing	Writing
Dressing (upper)	Speech Intelligibility
Dressing (lower)	
Toileting	**Cognitive Function**
Bladder	Problem Solving
Bowel	Memory
	Orientation
Mobility	Attention
Bed/Chair Transfers	Safety Judgement
Toilet Transfers	
Bath Transfers	**Psychosocial**
Car Transfers	Social Interaction
Locomotion	Emotion
Stairs	Adjustment to Limits
Community Mobility	Employability

Table 3.2 Functional Assessment Measure scoring

	Score	Description
Independent	7	Complete independence
	6	Modified independence
Dependent	5	Supervision or set up
	4	Minimal contact assistance
	3	Moderate assistance
	2	Maximal assistance
	1	Total assistance

3.3 SECTION ONE OF THE EUROPEAN HEAD INJURY EVALUATION CHART

The majority of information gathered in this section was done retrospectively from the acute medical notes and took an average of 30-45 minutes to complete per case. This did not include the time required to obtain the required case notes. Data in this and subsequent chapters were managed in MS Excel (Version 7) and Paradox for Windows (Version 4.5) and analysed in SPSS for Windows (Version 7.5).

DESCRIPTIVE DATA

Figure 3.1 shows the age distribution at injury. The median age of the sample at the time of injury was 30 years (mean=31, SD=17) with a range of 14-77 years. Just over half the sample were under 30 years of age and a smaller peak was evident in the 51-60 year olds. The male to female ratio was 3.7:1.0.

Figure 3.1 Age distribution at injury (n=47)

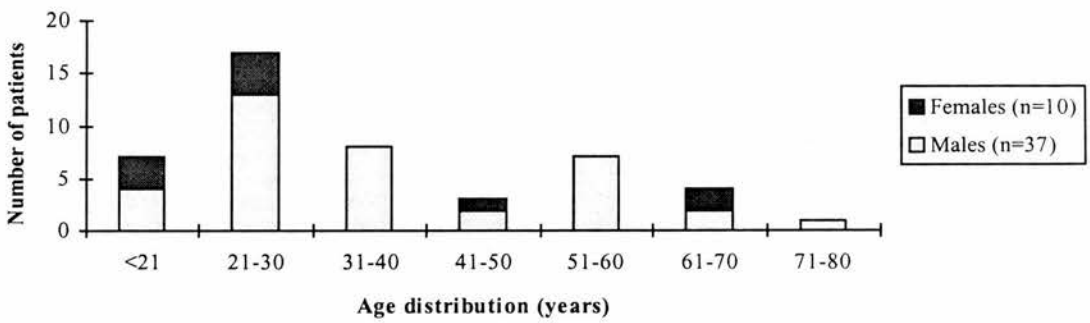


Table 3.3 illustrates the marital status of patients at the time of the TBI and reveals that just over half were single, reflecting the young age of the sample. Three quarters of patients were employed or in education (Table 3.4). Two-thirds were in skilled, intermediate or professional occupations and one third were classified as unskilled or semi-skilled. The majority of patients (n=37) had received education to secondary school level. Of the remainder, two were still in school, seven had undertaken higher education and no information was available on one.

Table 3.3 Marital status at TBI

Marital status	n (%)
Single	24 (51)
Married	14 (30)
Cohabiting	4 (9)
Widowed	2 (4)
Separated/divorced	3 (6)
Total	47 (100)

Table 3.4 Occupational status and class at TBI

Occupational status	n (%)	Occupational class	n (%)
Working full-time	29 (62)	Professional	3 (6)
Working part-time	1 (2)	Intermediate	3 (6)
Unemployed - seeking work	3 (6)	Skilled - non manual	7 (15)
Unemployed - ill-health	4 (9)	Skilled - manual	18 (38)
Retired	4 (9)	Semi-skilled	12 (26)
Student	5 (11)	Unskilled	2 (4)
Missing	1 (2)	Missing	2 (4)
Total	47 (101)	Total	47 (99)

Information relating to the patient's pre-traumatic situation (Items 12-22, see Appendix A) is illustrated in Table 3.5, and reveals that almost a quarter of patients had alcohol or drug problems, and one in seven had family problems.

Table 3.5 Pre-traumatic situation (n=47)

Problem	n (%)
Surgical/medical problems	3 (6)
Previous head injury with sequelae	0 (0)
Psychiatric problems	2 (4)
Epilepsy	3 (6)
Addiction to drugs and/or alcohol	11 (23)
Pre-existing physical or sensory disability	2 (4)
Pre-existing intellectual disability	1 (2)
Family problems	7 (15)
Social problems	3 (6)
Vocational or educational problems	4 (9)

INJURY DETAILS

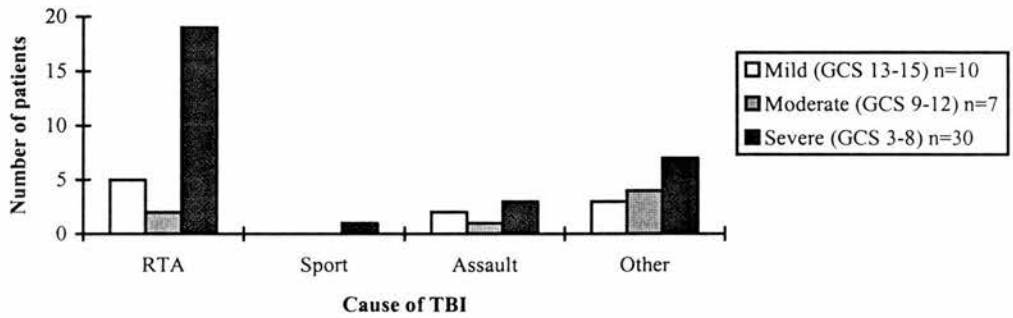
Cause of Traumatic Brain Injury

The majority of injuries were due to road traffic accidents (RTAs), more than half of which were pedestrian injuries (Table 3.6). The second most common cause was falls, although not a category present in the EHIEC, it accounted for all those coded as 'Other' (Item 23). Six patients were injured at work and four whilst travelling to or from work. In three cases, a relative or friend was injured in the RTA, and on one occasion a friend was killed. Figure 3.2 illustrates the cause of TBI by injury severity and reveals that the severe injuries tend to be associated with RTAs.

Table 3.6 Cause of injury

Category	n (%)
Vehicle driver	6 (13)
Vehicle passenger	3 (6)
Pedestrian	14 (30)
Motorbike	2 (4)
Bicycle	1 (2)
Sport/recreation	1 (2)
Domestic	0 (0)
Assault	6 (13)
Other	14 (30)
Total	47 (100)

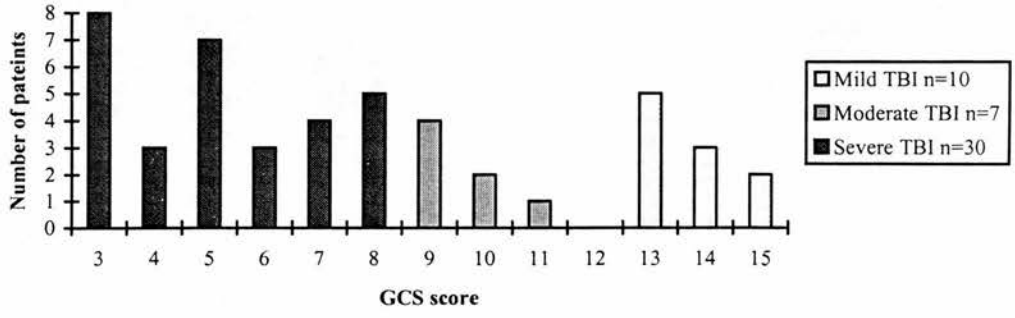
Figure 3.2 Cause of TBI by severity of injury (n=47)



Injury severity

Injury severity is described in the EHIEC by the worst GCS score in the first 24 hours, length of PTA and length of coma (Items 26-28). Based on GCS scores, 64% of patients sustained a severe TBI (GCS 3-8), 15% a moderate TBI (GCS 9-12) and 21% a mild TBI (GCS 13-15) (Figure 3.3).

Figure 3.3 Worst GCS score in first 24 hours after injury (n=47)



Duration of PTA was routinely measured in the neurorehabilitation unit using the Galveston Orientation and Amnesia Test (GOAT) (Levin et al. 1979b). Three quarters of patients had a PTA of more than 24 hours, indicating a severe injury, and the majority had a PTA of greater than one week (Table 3.7). It was not possible to assess PTA in seven patients, one of whom refused to co-operate with testing, and the remainder had severe communication and cognitive difficulties. A Spearman's rank correlation (r_s) between the GCS score and PTA category revealed a significant relationship ($r_s = -0.64$, $p<0.001$). Data relating to length of coma are not presented as this information could not be accurately ascertained from the medical notes in many cases.

Table 3.7 Duration of post-traumatic amnesia

Duration of PTA	n (%)
0-1 hour	1 (2)
1-24 hours	2 (4)
1-7 days	5 (11)
8-14 days	2 (4)
15-28 days	7 (15)
29-60 days	8 (17)
>60 days	15 (32)
Unassessable	7 (15)
Total	47 (100)

Intracranial and extracranial injuries, complications and initial management

Table 3.8 illustrates injuries to the brain, divided into haematoma and other intracranial lesions (Items 36, 37). Focal haemorrhagic contusions were the most common intracranial lesion and were present in almost a third of the population. Subdurals were the most frequent form of haematoma. Thirty four percent had no identifiable intracranial lesions on scanning, but are likely to have sustained diffuse axonal injury only evident at post mortem. A third of patients underwent neurosurgical intervention (other than ICP monitoring), the majority of whom required the evacuation of a haematoma (Item 39). Eight patients sustained basal fractures, 15 had linear skull fractures, four had depressed fractures and seven had 'other' fractures (Items 33, 34). A third of patients had sustained diffuse damage and no patient had penetrating injuries (Item 35). Item 38 in the EHIEC asks for the site of major damage to the brain but it was not possible to allocate this in a quarter of cases despite obtaining the acute neurosurgical case records.

Table 3.8 Intracranial injuries

Haematoma	n (%)	Other intracranial lesions	n (%)
None	26 (55)	None	16 (34)
Extradural	3 (6)	Focal haemorrhagic contusions	15 (32)
Subdural	7 (15)	Diffuse haemorrhagic contusions	10 (21)
Intracranial	4 (9)	Other focal lesions	0 (0)
Combination	7 (15)	Other diffuse lesions	3 (6)
Total	47 (100)	Combination	3 (6)
		Total	47 (99)

Details of extracranial injuries, complications and initial management are listed in Table 3.9 (Items 29-32, 40-52). Face and jaw injuries were sustained by more than half the sample and injuries to the thorax and limbs by around a quarter. The most common form of complication was a chest infection. Three quarters of patients required artificial ventilation and sedation, and almost half had a tracheostomy.

Table 3.9 Extracranial injuries, early complications and management (n=47)

	n (%)
Injuries	
Thorax	14 (30)
Abdomen	7 (15)
Pelvis†	7 (15)
Spine†	5 (11)
Right upper limb†	10 (21)
Left upper limb†	12 (26)
Right lower limb†	12 (26)
Left lower limb†	12 (26)
Face or jaw†	25 (53)
Burns	0 (0)
Complications	
Cardiovascular†	7 (15)
Pulmonary†	32‡ (68)
Infections (other than pulmonary) †	11 (23)
Management	
Tracheostomy	22 (47)
Assisted ventilation	35 (75)
Deterioration of conscious level	12 (26)
Early sedation†	35 (75)

† includes more than a yes/no response

‡ 18 of which were infections

3.4 SECTION TWO OF THE EUROPEAN HEAD INJURY EVALUATION CHART

Section Two of the EHIEC was completed at discharge from the rehabilitation unit and on a subgroup at 15 months post-injury. Data was collected by interview with the patient and carer and took on average one and a half to two hours to complete. The assessment at discharge took place at a median interval of 86 days after injury (mean=119, range=14-332 days). The follow up examination was scheduled for 15 months post-injury plus or minus one month (i.e. 425-486 days) and the median time between injury and follow up was 453 days (mean=460, range=399-522 days).

COMPLICATIONS

Table 3.10 presents the complications at discharge and follow up (Items 61-68), the most common of which was post-traumatic epilepsy. Cutaneous lesions were also prevalent at discharge, although more than half were only residual scars and the remainder were sores which required nursing care. Other complications included orthopaedic problems and visual deficits. The EHIEC also contains a section on current medication and clinical management (Items 69-82), the data from which is not presented here.

Table 3.10 Complications at discharge and follow up

	Discharge (n=47)	**Follow up (n=35)**
Complication	n (%)	n (%)
Post traumatic epilepsy†	10 (21)	4 (12)
Meningitis/encephalitis†	2 (4)	0 (0)
Hydrocephalus†	3 (6)	0 (0)
Chronic subdural haematoma†	1 (2)	0 (0)
Urinary†	2 (4)	1 (3)
Cutaneous†	9 (19)	2 (6)
Other	14 (30)	2 (6)

† includes more than a yes/no response

PHYSICAL STATE EXAMINATION

The EHIEC requires that the patient's neurological state is examined by a doctor (Items 83-97). The majority of items are scored on a three point scale based on the patient's ability to perform basic ADL (Table 3.11).

Table 3.11 Scoring system for physical state examination

Description	Score
No impairment, no disability	0
Mild/Moderate: independent daily function still possible in basic ADL	1
Severe: prevents independence in at least one basic ADL	2

Some items such as hemiparesis, spasticity and visual acuity have a scoring system allowing left and right to be specified. However in order to present the data, the response categories have been abbreviated to the more basic EHIEC scoring of none, mild/moderate and severe (Table 3.12). At both discharge and follow up, around half the patients had limb weakness and spasticity although the severity had decreased by follow up. Three fifths had gait disturbances and little improvement was noted between assessments.

Table 3.12 Physical state examination at discharge and follow up

	None	Mild/Moderate	Severe	Unassessable
Deficit	n (%)	n (%)	n (%)	n (%)
Hemiparesis				
Discharge (n=47)	22 (47)	14 (30)	11 (23)	0 (0)
Follow up (n=35)	18 (51)	13 (37)	4 (11)	0 (0)
Spasticity				
Discharge (n=47)	23 (49)	13 (28)	11 (23)	0 (0)
Follow up (n=35)	19 (54)	13 (37)	3 (9)	0 (0)
Peripheral paralysis				
Discharge (n=47)	44 (94)	2 (4)	1 (2)	0 (0)
Follow up (n=35)	33 (94)	2 (6)	0 (0)	0 (0)
Cerebellar syndrome				
Discharge (n=47)	32 (68)	8 (17)	3 (6)	4 (9)
Follow up (n=35)	26 (74)	7 (20)	0 (0)	2 (6)
Gait disturbance				
Discharge (n=47)	18 (38)	8 (17)	21 (45)	0 (0)
Follow up (n=35)	14 (40)	6 (17)	15 (43)	0 (0)
Chronic pain				
Discharge (n=47)	37 (79)	6 (13)	4 (9)	0 (0)
Follow up (n=35)	31 (89)	4 (11)	0 (0)	0 (0)
Limb movements†				
Discharge (n=47)	29 (62)	15 (32)	3 (6)	0 (0)
Follow up (n=35)	24 (69)	10 (29)	1 (3)	0 (0)

†Reduced amplitude of limb movements (orthopaedic cause)

Around a quarter had visual acuity, visual field or olfactory/gustatory deficits at both assessments (Table 3.13). It must be noted that only a subset of patients were able to be followed up at 15 months post-injury, and it may be that only those with ongoing problems returned for further assessment.

Table 3.13 Cranial nerve examination at discharge and follow up

Deficit	None n (%)	Mild/Moderate n (%)	Severe n (%)	Unassessable n (%)
Visual acuity				
Discharge (n=47)	34 (72)	5 (11)	5 (11)	0 (0)
Follow up (n=35)	24 (6)	5 (14)	3 (9)	3 (9)
Visual field				
Discharge (n=47)	36 (77)	5 (11)	2 (4)	4 (9)
Follow up (n=35)	27 (77)	1 (3)	3 (9)	4 (11)
Oculo-motor				
Discharge (n=47)	41 (87)	3 (6)	1 (2)	2 (4)
Follow up (n=35)	33 (94)	0 (0)	1 (3)	1 (3)
Auditory				
Discharge (n=47)	47 (100)	0 (0)	0 (0)	0 (0)
Follow up (n=35)	35 (100)	0 (0)	0 (0.0)	0 (0)
Olfactory/gustatory				
Discharge (n=47)	35 (75)	12 (26)	0 (0)	0 (0)
Follow up (n=35)	26 (74)	7 (20)	0 (0)	2 (6)
Other cranial nerve				
Discharge (n=47)	43 (92)	4 (9)	0 (0)	0 (0)
Follow up (n=35)	34 (97)	1 (3)	0 (0)	0 (0)

COGNITIVE STATUS

Cognitive status is examined by two methods in the EHIEC: practical tests completed by the patient and assessment by the patient, carer and examiner.

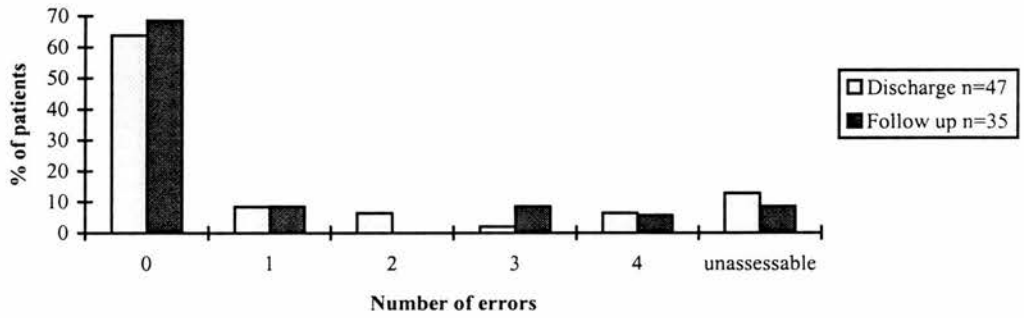
Tests of cognitive status

Seven areas of cognitive status are tested: mental control, verbal fluency, reading, writing, orientation, memory and learning and logical reasoning. Unfortunately details of the normal ranges are provided for only a minority of items. The percentage of the current sample who were unable to complete each test because of cognitive or communication difficulties is given.

Mental control

Mental control (Item 99) is assessed by asking the patient to perform serial sevens from 100-72. This involves the subject subtracting seven from 100, then seven from this answer and so on. The number of errors made is recorded. At discharge, 13% could not be assessed and this fell to 9% at follow up. Figure 3.4 illustrates the number of errors at discharge and follow up, and no significant difference was found between the two assessments (Wilcoxon signed rank test: Z= -0.513, p=0.608).

Figure 3.4 Assessment of mental control at discharge and follow up



Verbal fluency

Verbal fluency (Item 102) is assessed by asking the patient to produce the names of as many types of animal as possible in 60 seconds. At discharge, 13% could not be assessed and this fell to 9% at follow up. The mean and median scores are shown in Table 3.14, and a statistically significant improvement was found between assessments (Wilcoxon signed rank test: Z= -3.19, p=0.001). The EHIEC indicates that a normal score ranges from 14-22. Of the patients assessed, 46% produced 14 or more words at discharge and this rose slightly to 50% at follow up.

Table 3.14 Verbal fluency: number of animals produced at discharge and follow up

	Mean (SD)	Median	Range
Discharge† (n=41)	13 (7)	13	2-27
Follow up‡ (n=32)	16 (7)	14	3-33

† 6 patients unassessable; ‡ 3 patients unassessable

Reading

Patients are asked to read aloud a short paragraph to allow assessment of their reading skills (Table 3.15) (Item 103). No difference was found between discharge and follow up (Z= -0.557, p=0.577).

Table 3.15 Reading skills at discharge and follow up

	Discharge (n=47)	Follow up (n=32)
	n (%)	n (%)
No problem	31 (66)	27 (77)
Mild/Moderate problem	4 (9)	0 (0)
Severe problem	3 (6)	4 (11)
Unassessable	9 (19)	4 (11)

Writing

Patients are asked to write a sentence of their own to assess content and legibility (Table 3.16) (Item 104). No significant difference was found between assessments (Z= -1.68, p=0.094).

Table 3.16 Writing skills at discharge and follow up

	Discharge (n=47)	**Follow up (n=35)**
	n (%)	n (%)
No problem	15 (32)	17 (49)
Mild motor problem	5 (11)	3 (9)
Severe motor problem	4 (9)	2 (6)
Mild/Moderate impairment of spelling/syntax	9 (19)	4 (11)
Severe impairment of spelling/syntax	2 (4)	3 (9)
Combination	1 (2)	1 (3)
Unassessable	11 (23)	5 (14)

Orientation

To assess orientation, patients are asked for the day, date and place of examination (Table 3.17) (Item 106). No significant difference was found between the two assessments (Z= -0.372, p=0.710).

Table 3.17 Orientation at discharge and follow up

	Discharge (n=47)	**Follow up (n=35)**
	n (%)	n (%)
No problem	27 (57)	24 (69)
Mild/Moderate	8 (17)	4 (11)
Severe	6 (13)	4 (11)
Unassessable	6 (13)	3 (9)

Memory and learning

Separate verbal and visual tests are used to assess memory and learning. The verbal test (Items 107-109,128) involves learning a list of ten words, over three repetitions, and then recalling them some time later although no time interval is specified in the EHIEC. At discharge, 13% could not be assessed and this fell to 9% at follow up. A statistically significant improvement between assessments was found in the number of words learned following each repetition, but not for the number recalled (Table 3.18). The EHIEC states that a normal score at recall is at least five words. Of those who completed the assessment in this sample, 51% scored at or above this minimum at discharge and 50% at follow up.

Table 3.18 Verbal memory: mean number of words listed at discharge and follow up

	Discharge‡ (n=41)		Follow up^ (n=32)		p value (sig level†)
	Mean (SD)	Range	Mean (SD)	Range	
First repetition	5.0 (2.0)	0-9	5.7 (1.9)	1-9	0.05 (*)
Second repetition	5.9 (2.5)	0-10	6.9 (2.1)	1-10	0.004 (**)
Third repetition	6.5 (2.7)	0-10	7.5 (2.3)	2-10	0.003 (**)
Recall	4.7 (2.9)	0-10	5.3 (3.1)	0-10	0.091 (NS)

† NS=non-significant, *=p<0.05, **=p<0.01; ‡ 6 patients unassessable; ^ 3 patients unassessable

The visual test (Items 110, 129) involves copying a figure of three interconnecting triangles then recalling this some time later, although again no time interval is specified. At discharge 23% were not able to be assessed and this fell to 14% at follow up. The mean scores did improve slightly between discharge and follow up but were not found to be significantly different (Table 3.19).

Table 3.19 Visual memory and learning: mean score at discharge and follow up

	Discharge‡ (n=36)		Follow up^ (n=30)		p value (sig level†)
	Mean (SD)	Range	Mean (SD)	Range	
Copy	5.6 (1.1)	1-6	5.9 (0.4)	4.5-6	0.08 (NS)
Recall	4.4 (1.7)	0-6	4.7 (1.4)	1-6	0.27 (NS)

† NS=non-significant; ‡ 11 patients unassessable; ^ 5 patients unassessable

Logical reasoning

Logical reasoning is assessed by asking the patient two questions (Items 111,112). The first involves the addition of numbers within a short sentence, and the second describing the association between a car and a boat (Table 3.20). Although the percentage of patients scoring correctly decreased from discharge to follow up for both items, these differences were not found to be significant.

Table 3.20 Logical reasoning at discharge and follow up

	Discharge (n=47)	Follow up (n=35)
	n (%)	n (%)
Addition		
Correct	19 (40)	12 (34)
Incorrect	22 (46)	20 (57)
Unassessable	6 (13)	3 (9)
Association		
Correct	17 (36)	11 (31)
Incorrect	24 (51)	21 (60)
Unassessable	6 (13)	3 (9)

Cognitive assessment by patient, carer and examiner

This section involves the subjective assessment of attention, understanding, form of thinking, loss of self criticism, denial, executive functions and communication by the patient, carer and examiner (Items 98, 100, 101, 113-116). All except for communication are assessed on the three point scoring system as detailed in Table 3.21 which indicates that if the patient or carer has noted a problem in the last month the score is one, but if the problem is observed by the examiner, or another clinician, the score is two.

Table 3.21 Scoring system for cognitive assessment

Description	Score
None	0
Mild/Moderate: reported by the patient or carer during the last month but not observed by the examiner	1
Severe: observed by the examiner or other clinician	2

Table 3.22 presents the results of cognitive assessment at discharge and follow up. It shows that Understanding and Executive functions appear to have improved between discharge and follow up and this was confirmed statistically (Understanding: Z= -3.39, p=0.001, Executive functions: Z= -2.71, p=0.007). No significant differences were found for any other area of assessment.

Table 3.22 Cognitive assessment at discharge and follow up

	No problem n (%)	Mild/Moderate n (%)	Severe n (%)	Unassessable n (%)
Attention				
Discharge (n=47)	15 (32)	9 (19)	23 (49)	0 (0)
Follow up (n=35)	16 (46)	4 (11)	15 (43)	0 (0)
Understanding				
Discharge (n=47)	23 (49)	8 (17)	16 (34)	0 (0)
Follow up (n=35)	30 (86)	0 (0)	5 (14)	0 (0)
Form of thinking				
Discharge (n=47)	30 (64)	2 (4)	9 (19)	6 (13)
Follow up (n=35)	25 (71)	1 (3)	6 (17)	3 (9)
Loss of self criticism				
Discharge (n=47)	27 (57)	6 (13)	9 (19)	5 (11)
Follow up (n=35)	21 (60)	4 (11)	7 (20)	3 (9)
Denial/anosognosia				
Discharge (n=47)	18 (38)	7 (15)	17 (36)	5 (11)
Follow up (n=35)	18 (51)	0 (0)	15 (43)	2 (6)
Executive functions				
Discharge (n=47)	31 (66)	7 (15)	5 (11)	4 (9)
Follow up (n=35)	30 (86)	3 (99)	1 (3)	1 (3)

Communication (Item 100) is assessed as shown in Table 3.23. No significant difference was noted between discharge and follow up (Z= -1.289, p=0.197).

Table 3.23 Communication problems at discharge and follow up

	Discharge (n=47)	Follow up (n=35)
	n (%)	n (%)
No problem	26 (55)	18 (51)
Mild dysarthria, dysphonia	6 (13)	6 (17)
Severe dysarthria, dysphonia	1 (2)	1 (3)
Mild aphasia allowing usual speech	2 (4)	2 (6)
Severe aphasia preventing usual speech	8 (17)	4 (11)
Combination	4 (9)	4 (11)

AFFECTIVE AND BEHAVIOURAL STATE

This section examines loss of emotional self control, mental excitement, lack of personal hygiene, avolition, depression and anxiety (Items 117-122). Assessment is by the examiner and carer but the opinion of the patient is excluded. Problems are only scored as present if they have appeared or increased since the injury and the majority of items are scored as shown in Table 3.24.

Table 3.24 Scoring for affective and behavioural state examination

Description	Score
None	0
Reported by carer, regarding the past month	1
Observed by examiner	2

No obvious improvement or deterioration was noted between discharge and follow up, and this was confirmed by performing a Wilcoxon signed rank test for each item (Table 3.25).

Table 3.25 Affective and behavioural state of patient at discharge and follow up

	No problem	Carer†	Examiner‡	Unassessable
	n (%)	n (%)	n (%)	n (%)
Loss of self control				
Discharge (n=47)	28 (60)	14 (30)	2 (4)	3 (6)
Follow up (n=32)	19 (54)	14 (40)	1 (3)	1 (3)
Mental excitement				
Discharge (n=47)	39 (83)	2 (4)	3 (7)	3 (6)
Follow up (n=32)	33 (94)	1 (3)	0 (0)	1 (3)
Poor hygiene				
Discharge (n=47)	35 (75)	8 (17)	0 (0)	4 (9)
Follow up (n=32)	29 (83)	3 (9)	1 (3)	2 (6)
Avolitional				
Discharge (n=47)	25 (53)	9 (19)	10 (21)	3 (6)
Follow up (n=32)	18 (51)	12 (34)	4 (11)	1 (3)
Depression				
Discharge (n=47)	30 (64)	10 (21)	3 (6)	4 (9)
Follow up (n=32)	20 (57)	10 (29)	3 (9)	2 (6)
Anxiety				
Discharge (n=47)	27 (58)	11 (23)	5 (11)	4 (9)
Follow up (n=32)	22 (63)	11 (31)	1 (3)	1 (3)

† problem noted by carer; ‡ problem noted by examiner

Grief and mourning

The examiner is asked to assess the patient and relative's Grief and mourning process (Items 124, 125) at discharge and follow up (Table 3.26). A significant improvement was found in the patient's degree of acceptance between the two assessments ($Z= -3.87$, $p<0.001$). In general, relatives showed satisfactory acceptance at the time of discharge and no significant change was found by follow up but this item was subject to a large amount of missing data where no relative was available.

Table 3.26 Assessment of grief and mourning at discharge and follow up

	Patient's grief		Relative's grief	
	Discharge	Follow up	Discharge	Follow up
	n (%)	n (%)	n (%)	n (%)
Satisfactory acceptance	18 (38)	24 (69)	27 (57)	24 (69)
Insufficient acceptance	15 (32)	8 (23)	3 (6)	0 (0)
No acceptance	6 (13)	0 (0)	0 (0)	0 (0)
Unable to assess	8 (17)	3 (9)	17† (36)	11† (31)
Total	47 (100)	35 (100)	47 (99)	35 (100)

† no relative available

ACTIVITIES OF DAILY LIVING

Activities of daily living are assessed on a four point scale classified by level of dependence (Table 3.27).

Table 3.27 Scoring for ADL

Description	Score
Normal/independent	0
Independent but some diminution (e.g. slowness or need for technical help)	1
Partly independent (e.g. needs human help or stimulation some of the time)	2
Severe dependence (e.g. needs human help or stimulation most of the time)	3

Items are split into basic and advanced ADL (Items 131-142). Table 3.28 presents the ADL scores at discharge and follow up and all items, except for driving, cover the full range of scores (0-3). Scores for basic ADL items are lower than advanced items and reveal that patients were independent in basic ADL at discharge and follow up, but required some help

particularly at discharge for advanced ADL. Wilcoxon signed rank tests for each item revealed statistically significant improvements at the $p<0.01$ level between assessments for toileting, mobility outside the home, shopping and use of public transport.

Table 3.28 Mean ADL scores at discharge and follow up

	Discharge (n=47)		Follow up (n=35)		p (sig level†)
	Mean (SD)	Median	Mean (SD)	Median	
Basic ADL					
Eating, drinking	0.8 (1.0)	0.0	0.8 (1.0)	0.0	1.000 (NS)
Sphincter control	0.6 (1.1)	0.0	0.5 (1.1)	0.0	0.157 (NS)
Toileting	1.1 (1.1)	1.0	0.8 (1.1)	0.0	0.001 (***)
Dressing	1.2 (1.1)	1.0	1.0 (1.1)	1.0	0.166 (NS)
Transfers	0.9 (1.1)	0.0	0.8 (1.0)	0.0	0.257 (NS)
Mobility at home	1.1 (1.1)	1.0	0.9 (1.0)	1.0	0.035 (*)
Advanced ADL					
Mobility outside	1.6 (1.3)	2.0	1.4 (1.3)	1.0	0.005 (**)
Going out shopping	1.8 (1.2)	2.0	1.5 (1.3)	1.0	0.003 (**)
Using public transport	1.8 (1.2)	2.0	1.5 (1.3)	2.0	0.006 (**)
Driving a car	3.0 (0.0)	3.0	2.7 (0.9)	3.0	0.059 (NS)
Writing a letter	1.4 (1.2)	1.0	1.4 (1.2)	1.0	1.000 (NS)
Financial management and administrative tasks	1.4 (1.1)	1.0	1.4 (1.3)	1.0	0.819 (NS)

† NS=non-significant, *=p<0.05, **=p<0.01, ***=p<0.001

Distributional characteristics of Activities of Daily Living items

Table 3.29 presents details of the distributional characteristics of the ADL items at discharge and follow up. It shows that, with the exception of driving, a notable percentage of the sample scored at the ceiling level (i.e. where no further improvement would be evident on the EHIEC) at both assessments for basic and advanced ADL. For advanced ADL, floor effects (i.e. where any deterioration would not be evident on the EHIEC) were found at both discharge and follow up.

Table 3.29 Distributional characteristics of ADL items at discharge (n=47) and follow up (n=35)

	Ceiling		Floor	
	Discharge n (%)	Follow up n (%)	Discharge n (%)	Follow up n (%)
Basic ADL				
Eating, drinking	27 (57)	21 (60)	4 (9)	2 (6)
Sphincter control	34 (72)	27 (77)	6 (13)	4 (11)
Toileting	18 (40)	19 (54)	7 (15)	5 (14)
Dressing	17 (36)	17 (49)	6 (13)	4 (11)
Transfers	25 (53)	18 (51)	6 (13)	4 (11)
Mobility at home	18 (38)	15 (43)	6 (13)	4 (11)
Advanced ADL				
Mobility outside	14 (30)	13 (37)	18 (38)	11 (31)
Going out shopping	9 (19)	13 (37)	19 (40)	12 (34)
Using public transport	11 (23)	13 (37)	19 (40)	13 (37)
Driving a car	0 (0)	3 (9)	47 (100)	31 (89)
Writing a letter	17 (36)	12 (34)	13 (28)	10 (29)
Financial management and administrative tasks	13 (28)	13 (37)	11 (23)	10 (29)

FAMILY AND RELATIVES

This section covers items relevant to the family and living situation (Items 146-151) (Table 3.30). It was only possible to complete this section with 30 cases at discharge and 24 at follow up as a close relative was not always available for interview.

Table 3.30 Family issues at discharge and follow up

	Discharge (n=30)	Follow up (n=24)
	n (%)	n (%)
Family had to seek help/medication for themselves	13 (43)	2 (8)
Family incurred additional expenses	14 (47)	10 (42)
Family member had to modify work or education	10 (33)	5 (21)
Significant change in family roles	4 (13)	3 (13)
Behavioural problems in uninjured children	2 (7)	1 (4)
Need for partial or permanent respite care	4 (13)	2 (8)

An assessment of the relative's behaviour is required for the EHIEC (Item 152) and the great majority of relatives were found to be appropriate at both discharge and follow up (Table 3.31).

Table 3.31 Relative's behaviour at discharge and follow up

	Discharge (n=30)	Follow up (n=24)
	n (%)	n (%)
Appropriate	27 (90)	20 (83)
Over protective	1 (3)	2 (8)
Distant	1 (3)	1 (4)
Aggressive	0 (0)	0 (0)
Other	1 (3)	1 (4)

SUBJECTIVE DISTRESS OF THE PATIENT AND RELATIVE

The patient and relative are required to assess their subjective distress on a visual analogue scale (Items 130, 153) where zero equals no stress and six equals severe stress (Table 3.32). Although reported levels of subjective distress are higher for relatives than for patients, both decreased between assessments.

Table 3.32 Subjective distress of patient and relative at discharge and follow up

	Discharge	Follow up
Patient	n=40	n=32
Mean (SD)	3 (1.8)	2 (1.8)
Median	3	2
Range	0-6	0-6
Relative	n=30	n=22
Mean (SD)	4 (1.8)	3 (1.8)
Median	4	3
Range	0.5-6	0-6

QUALITY OF LIFE

At follow up, quality of life (QoL) was assessed on a visual analogue scale where zero equals not satisfied at all and ten equals very happy (Items 172-174). Both the patient and relative rated their own QoL and the relative was asked to give their view of the patient's QoL (Table 3.33). Spearman's rank correlations revealed no significant association between the two ratings on the patient's QoL ($r_s = 0.30$, p=0.306) but that there was a positive correlation between the relative's rating of their own QoL and their rating of the patient ($r_s = 0.63$, p=0.002).

Table 3.33 Patient and relative's quality of life at follow up

	Mean (SD)	Median	Range
Patient's QoL			
Patient's opinion (n=32)	6 (3.1)	5	0-10
Relative's opinion (n=23)	5 (2.6)	5	0-10
Relative's QoL			
Relative's opinion (n=22)	6 (2.3)	6	2-10

EDUCATION AND WORK

The education and work section of the EHIEC (Items 155-161) was only completed at follow up and it was found that only a quarter were working or in education (Table 3.34). Compared with the pre-injury figures, the percentage in work fell from 63% at injury to 17% at follow up whereas unemployment rose from 20% to 43%.

Table 3.34 Daily activity at follow up

Daily activity	n (%)
Working	6 (17)
School	2 (6)
Vocational/educational training	1 (3)
Unemployed	15 (43)
In hospital or nursing home	3 (9)
Retired	8 (23)
Total	35 (101)

The EHIEC also contains a short section on social aspects (covering problems with the police, alcohol and drugs, and leisure activities), medico-legal aspects and resources but results are not presented here (Items 162-171).

GLASGOW OUTCOME SCALE

The Glasgow Outcome Scale (GOS) (Jennett and Bond, 1975), a well known measurement tool in the field of TBI, is also included in the EHIEC (Item 175). However, the EHIEC uses different scoring subdivisions from the original GOS and the order of scoring is reversed. Using the system advised by the EHIEC, the mean GOS at discharge was 3.0 (SD=1.5, range 1-5) and at follow up was 2.6 (SD=1.7, range 0-5) (Table 3.35). The difference between assessments was found to be significant ($Z= -3.64$, $p<0.001$).

Table 3.35 Glasgow Outcome Scale scores (using EHIEC scoring)

	Discharge (n=47)	**Follow up (n=35)**
GOS category (score)	n (%)	n (%)
Good Recovery		
Upper level (0)	0 (0)	4 (11)
Lower level (1)	13 (28)	8 (23)
Moderate Disability		
Upper level (2)	5 (11)	4 (11)
Lower level (3)	6 (13)	5 (14)
Severe Disability		
Upper level (4)	14 (30)	10 (29)
Lower level (5)	9 (19)	4 (11)
Persistent Vegetative State (6)	0 (0)	0 (0)

3.5 FUNCTIONAL ASSESSMENT MEASURE

Tables 3.36 and 3.37 present the FIM+FAM scores at discharge and follow up. This data was routinely collected by the ward and therapy staff at discharge whilst follow up scores were determined by the author. Unfortunately some data was found to be missing at discharge due to the heavy workload faced by the clinical staff. Statistically significant improvement was found for stairs, reading, problem solving and safety judgement at $p<0.01$, but a deterioration was noted for dressing (upper).

Table 3.36 FIM+FAM Motor items at discharge and follow up

	Discharge (n=47)			Follow up (n=35)		
	n	Mean (SD)	Median	n	Mean (SD)	Median
Self Care						
Swallowing	47	6.5 (1.3)	7.0	35	6.9 (0.7)	7.0
Feeding	47	6.0 (1.7)	7.0	35	6.0 (1.6)	7.0
Grooming	47	5.7 (1.7)	6.0	35	5.8 (1.7)	7.0
Bathing	47	5.4 (1.9)	6.0	35	5.6 (1.8)	6.0
Dressing (upper)	47	6.0 (1.7)	7.0	35	5.6 (1.8)	6.0
Dressing (lower)	47	5.5 (1.9)	6.0	35	5.3 (2.0)	6.0
Toileting	47	5.4 (2.2)	7.0	35	5.8 (1.9)	7.0
Bladder	46	5.4 (2.2)	7.0	35	5.9 (2.2)	7.0
Bowel care	46	5.6 (2.1)	7.0	35	6.2 (1.9)	7.0
Mobility						
Bed Transfers	47	5.6 (2.2)	7.0	35	5.8 (1.8)	7.0
Toilet Transfers	46	5.4 (2.2)	7.0	35	5.8 (1.8)	7.0
Bath Transfers	46	5.1 (2.1)	6.0	35	5.2 (2.1)	6.0
Car Transfers	47	5.2 (2.3)	6.5	35	5.3 (2.2)	7.0
Locomotion	47	5.2 (2.0)	6.0	35	5.5 (1.8)	6.0
Stairs	47	4.9 (2.4)	6.0	35	5.3 (2.2)	6.0
Community Mobility	21	3.7 (2.4)	3.0	35	4.6 (2.0)	3.0

Table 3.37 FIM+FAM Cognitive items at discharge and follow up

	Discharge (n=47)			Follow up (n=35)		
	n	Mean (SD)	Median	n	Mean (SD)	Median
Communication						
Comprehension	47	5.7 (1.5)	6.0	35	5.7 (1.4)	6.0
Expression	47	5.3 (1.6)	6.0	35	5.6 (1.7)	6.0
Reading	47	4.9 (1.6)	5.0	35	5.5 (1.8)	6.0
Writing	47	4.7 (1.8)	5.0	35	5.0 (2.2)	5.0
Speech Intelligibility	46	5.8 (1.5)	6.0	35	5.9 (1.8)	7.0
Cognition						
Problem Solving	44	4.2 (1.9)	4.5	35	5.1 (1.7)	5.0
Memory	44	4.5 (1.8)	5.0	35	5.0 (1.8)	5.0
Orientation	44	5.3 (2.0)	6.0	35	5.8 (1.8)	7.0
Attention	44	4.8 (1.6)	5.0	35	5.1 (1.5)	5.0
Safety Judgement	45	4.6 (1.8)	5.0	35	5.3 (1.4)	5.0
Psychosocial						
Social Interaction	42	5.1 (1.9)	6.0	35	5.3 (1.5)	6.0
Emotion	42	4.9 (1.8)	6.0	35	4.6 (1.6)	5.0
Adjustment to Limits	43	4.5 (1.8)	5.0	35	5.1 (1.8)	5.0
Employability	23	3.7 (2.0)	4.0	35	4.4 (1.6)	4.0

3.6 DISCUSSION

The aim of this study was to explore the utility of the EHIEC as a comprehensive outcome measure and this section provides a discussion of this area. The actual results of this patient sample are therefore not explored in depth but are used to illustrate particular points.

GENERAL OVERVIEW

The EHIEC was designed to cover information pertinent to the patient and family, from the time of insult to several years post-injury. This is clearly a very difficult task given the breadth of problems experienced by this population, and is reflected in the length of the EHIEC and the time required for its completion. Thus, although the originators stated that the chart could be completed in one to two hours, experience in this study suggested that two to three hours was actually required. In an early rehabilitation unit, such as the one this study was based in, the length of time to complete the EHIEC would make it impractical for routine use. However, this may not be so for other centres.

The EHIEC does cover the areas most relevant to the TBI population. However, the length, structure, crude scoring system and lack of definitions and guidelines make it cumbersome to use in practice. It generates a large amount of data which is readily stored on a computer but is not easily displayed for use in a clinical setting. Although the EHIEC is purported to be reliable, valid and sensitive, there is little published evidence to support this (Truelle et al. 1992; Truelle, 1993).

Because of the number of items in the EHIEC, Section One and those parts of Section Two assessing the patient's physical, cognitive, affective and behavioural status are focused on in this research. To further explore the potential users' understanding and interpretation of items in the EHIEC, a small study of the unit's rehabilitation staff was undertaken (n=15). This involved mailing a selection of questions from the EHIEC to members of each rehabilitation profession and asking for their interpretation of the item. Results of this study are provided in the following sections.

SECTION ONE

Section One of the EHIEC collects information relating to the patient's pre-traumatic situation, circumstances of the injury and initial management. This section, as suggested by the originators, should preferably be completed during the acute hospital stay rather than

retrospectively from the medical notes. This is particularly important for items relating to the severity of TBI, such as GCS, length of coma and PTA, or where accurate neuroradiological information is required, for example when defining the site of major intracranial damage. Where the rehabilitation unit receives all its patients from one acute neurosurgical centre, it should be feasible to encourage the use of Section One in the admitting unit.

Suggested changes to this section relate mainly to clarification of items and scoring. For example in the part documenting the patient's pre-traumatic situation, 'Addiction' (Item 17) and 'Mental disability' (Item 19) are not defined although the examiner is asked to determine whether there are 'significant functional consequences' relating to these areas. As definitions and guidelines already exist for both these items, it may be appropriate that they be applied here and ensure that a consistent approach is taken by all examiners. Similarly, occupation could be recorded using a readily available classification system (Office of Population Census and Surveys, 1991). The item on cause of injury (Item 23), omits a category for 'Falls' which are known to be a very common cause of TBI (Jennett et al. 1979b; Jennett, 1996). It is therefore suggested that this be included in a revised version of the EHIEC. The items describing 'Extracranial injuries' would also benefit from further clarification (Items 43-52). For example, the examiner is asked to document injuries to the abdomen or limbs, but no guidelines are provided on the type or severity to be included.

In summary, Section One was found to adequately cover areas relevant to the TBI individual but many items require more precise definitions and scoring guidelines.

SECTION TWO

General

While it is accepted that obtaining information from a carer is a valuable feature of the EHIEC, it is unclear whether joint interviews with the patient and carer, or separate interviews were envisaged. As Section Two contains a mixture of test items for the patient, and questions for the carer and/or relative, administration is somewhat cumbersome. In this study the EHIEC was re-structured in order to assist questionnaire completion. This mainly involved grouping items relevant to the patient or carer.

Physical state examination

The physical state examination (Items 83-97) has been based on disabilities criteria (World Health Organisation, 1980) relating to basic ADL in order to plan clinical management. However, this focus makes assessment very difficult, inappropriate or impossible. For example, the examiner must assess the effect of a single impairment, such as hemiparesis, visual field or olfactory deficit, on ADL items such as dressing or eating. Use of pre-existing impairment based scales may provide more meaningful, accurate and sensitive data. For example, it would be possible to incorporate traditional scoring systems, familiar to physicians, such as Medical Research Council grading of muscle weakness or Snellen charts for recording visual acuity. As a separate section assessing ADL already exists in the current EHIEC it would seem possible to base the physical examination primarily on impairment. The physical state assessment, and other parts of the EHIEC, use the terms mild/moderate and severe to indicate severity of the impairment or disability under assessment. Whilst brief guidelines are provided for their differentiation, the use of this terminology is notoriously inconsistent in rehabilitation practice and is best avoided unless strictly defined (Wanlass et al. 1992).

Cognitive state

Ease of use of the EHIEC was found to vary with severity of TBI, particularly for the cognitive examination. The originators collected data primarily from the very severely injured (GCS 3-5), although the time post-injury is not stated and the extent of missing data is not clear (Truelle et al. 1990; Truelle and Robert-Pariset, 1990; Truelle et al. 1992). This research found that it was not always possible to undertake full cognitive assessment due to visual, motor or language deficits. At the other end of the spectrum when assessing mild TBI, it was unclear whether deficits in higher level functioning would be adequately assessed by the current format (Cudmore and Pentland, 1996). It is acknowledged however that the EHIEC would not replace the need for detailed and expert neuropsychological assessment.

Cognitive tests

The cognitive tests in the EHIEC are reasonably straightforward to administer. However, normal ranges are only available for two of the tests and therefore interpretation of results is severely limited. In this sample, the majority of tests found no difference between discharge and follow up assessment. As with the physical state examination, it may be possible to use pre-existing tests to replace some items. For example, the verbal learning test (Item 107-

109, 128) which uses a set of ten words could be replaced by the Rey Auditory-Verbal Learning Test which uses 15 words and a very similar method (Rey, 1964). Similarly, the visual memory test (Items 110, 129) could be replaced by the Rey-Osterrieth Complex Figure (Rey, 1941) although it is recognised that this is a relatively time consuming assessment.

As mentioned previously, a small staff survey was undertaken in order to assess the understanding and interpretation of items and their scoring. One part of this survey involved respondents scoring the visual memory item and it was found that scores for the same drawing varied from one to six (possible range of 0-6). This has again highlighted the inadequacy of the current scoring guidelines and indicates that a more detailed scoring system is required to improve consistency.

The assessment of reading (Item 103) and writing (Item 104) needs to be reviewed. The former involves the patient reading a sentence aloud, and from this the examiner must assess both speech intelligibility and understanding, as indicated in Table 3.38. However, no guidance is given on how to rate understanding and this was found to be very difficult. To assess writing, the patient is asked to compose a sentence which is examined for content, spelling and grammar. However, variation in the complexity of the sentence written makes consistent scoring difficult and more detailed guidelines are required.

Table 3.38 Scoring of reading skills

Description	Score
No problem	0
Mild/Moderate: occasional omission or paralexia, but understands	1
Severe: at least one sentence unintelligible	2

Assessment of logical reasoning (Item 111-112) is also problematic as the response categories are limited to correct or incorrect with no guidelines on acceptable answers. A more precise scoring system might allow credit for partially correct responses.

Subjective assessment of cognition

It was usually possible to score patients on the non-test areas of cognitive function (e.g. attention). However the scoring system, which is based on whether the patient, relative or examiner reports the problem, is limited and may not adequately reflect the severity of the

area under assessment. A more sensitive scoring system is required to reflect the extent of the problem and its effect on daily life. Clarification is also required for certain items including the level of oral understanding (Item 101) which is determined by the question: 'Does he/she have difficulty (aphasia) in understanding what is said to him/her?' Whether this is specifically directed at recording only the presence or absence of receptive dysphasia or if it includes other difficulties in understanding, is not clear. In addition, whether it relates to basic or more complex information is not stated.

Affective and behavioural state

The scoring of the patient's affective and behavioural state is limited in a similar manner to the cognitive section, although here the patient's opinion is excluded. Further clarification is also required for items in this section, for example Mental excitement, talkativeness (Item 118) which is judged by the question: 'Does he/she talk rapidly and excessively without making much sense?'. All behavioural assessments are by their nature somewhat subjective, but the criteria need to be more precise. One item which already has a separate scoring style is Grief and mourning (Item 124, 125). This complex area was found to be very difficult to assess and little guidance is given. This was also highlighted as a problem in the staff survey. Bearing in mind that the EHIEC is designed to be filled in by any member of the rehabilitation team, more detailed assistance is required.

One feature which is lacking in the EHIEC, is the patient's own assessment of his symptoms. For example, a tool such as the Head Injury Symptom Checklist (Dikmen et al. 1993) was developed to assess the typical post-concussion problems such as headache, fatigue and intolerance to noise or light, and it would seem appropriate to include similar questions in the EHIEC.

Activities of Daily Living

This section contains no definitions of items or guidelines for assessment of basic and advanced ADL (Items 131-142) and therefore items are open to interpretation. For example, what is included in the assessment of Toileting or Transfers is not stated. Driving, which is included in advanced ADL, has the same scoring system as the other ADL items, however it must be questioned whether it is possible to be partly independent in driving which is defined as 'needs human help or stimulation some of the time'. Significant differences between discharge and follow up were found for one of the basic, and three of the advanced, ADL items indicating that patients had improved over this time.

Functional Assessment Measure

The FIM+FAM was also completed with patients providing a comparison with some EHIEC data. For ADL, the EHIEC contains a much shorter section than the FIM+FAM and does not specifically assess areas such as grooming or the ability to climb stairs. Unlike the FIM+FAM, the EHIEC provides no description of each activity and has a more limited scoring system. However, it is interesting to note that although the FIM+FAM is a more detailed measure, proportionally fewer significant results were found for its self care items than for the EHIEC, which has only a four point scoring system. This may relate to a bias towards independence in the scoring of the EHIEC, where two of the four possible responses indicate independence compared with only two of the seven responses in the FIM+FAM. Similar limitations are found in the Cognitive, and Affective and Behavioural state sections of the EHIEC, with severely limited item definition and scoring compared to the FIM+FAM.

Glasgow Outcome Scale

Rather than the conventional GOS, where a low score indicates a poor outcome, the EHIEC uses a reversed scoring system (Item 175). Why this has been done is not clear and makes comparison with other studies very difficult. Although the responsiveness of the GOS is limited because of the small number of response categories, it is one of the few recommended and commonly used measures in the TBI field (Clifton et al. 1992). On this basis, changing the scoring system and structure of the GOS would appear unjustified.

3.7 SUMMARY

Measurement tools are most easy to devise when they are measuring a single phenomenon for a single purpose. The consequences of TBI are many and varied so that developing a comprehensive assessment tool is exceedingly difficult, particularly when it is designed to serve so many purposes. The European Brain Injury Society aimed to develop a tool which was simple, specific and reliable, and usable by any member of a rehabilitation team. However the problems highlighted, particularly its length and insufficient guidelines, indicate that the current version does not meet these criteria (Cudmore and Pentland, 1996). Nevertheless, it does provide a potentially useful method of documenting premorbid state, circumstances surrounding the TBI, extent of injuries and early management. Although such information is usually provided in published studies, it is often not collected in such detail by other scales (Harvey and Jellineck, 1981; Hall et al. 1993; Pentland and

McPherson, 1994). There is merit in recording data in such a systematic way, as a number of workers evaluating outcomes have recommended (Rappaport et al. 1989; Hall and Johnston, 1994; Johnston and Hall, 1994).

Section Two is limited by the lack of item definition, insufficient guidelines and crude scoring systems. As the EHIEC is designed for serial use this latter point is of particular relevance. The originators argue that a very limited range of response categories makes the tool more simple to use by untrained staff and improves inter-rater reliability (Truelle and Robert-Pariset, 1990). While this may be true, it restricts the potential to monitor change and hence reduces responsiveness. However, the originators do suggest that the EHIEC is used in conjunction with other outcome scales, such as the FIM (Truelle and Robert-Pariset, 1990; Truelle, 1993), although clearly this would make the assessment process even lengthier.

There is no guidance on how to collate and present the EHIEC data recorded. At present it provides a 26 page record of scores, albeit amenable to computer storage. Some components may be suitable for numerical sum scoring or presentation in a histogram form. Such methods might enhance its usefulness by assisting interprofessional communication of information within the rehabilitation team.

Thus in its present form the EHIEC provides a potentially useful checklist for case record purposes. The major drawback to its routine clinical use is the time required for completion. For research purposes it has several disadvantages. Although it has face validity, a detailed instruction manual would be required to allow the necessary testing of its concurrent validity and reliability. The lack of a more sophisticated scoring system for several items severely limits its sensitivity to change over time. To adequately address these deficiencies would require extensive collaborative research with the authors of the EHIEC and other members of EBIS who currently use it.

The utility of the current version of the EHIEC is therefore very limited and it was decided to address the issue of evaluating the long term outcome after TBI using a different approach as discussed in subsequent chapters.

Chapter Four

Long term follow up of traumatically brain injured individuals by interview: Study population and methods

4.1 INTRODUCTION

There have been few studies of the longer term outcome of TBI patients after discharge from an in-patient rehabilitation programme (Thomsen, 1984; Rappaport et al. 1989; Masson et al. 1997). Of the studies undertaken, few have addressed issues from the perspective of the patient and relative/carer, which was the aim of this study. The objectives were:

1. to describe the major long term consequences of TBI using available outcome measures, focusing on perceived health status, functional assessment and community integration;
2. to assess the feasibility of using self-report measures in a TBI population several years after injury;
3. to assess outcome with regard to injury severity and time since TBI;
4. to compare the use and results of a health status assessment measure in TBI patients with the general population.

4.2 STUDY METHODOLOGY

ETHICAL APPROVAL

Prior to commencing the study, ethical approval was gained from the Lothian Research Ethics Committee (Psychiatry/Clinical Psychology Sub-Committee) and Fife Health Board Ethics Committee. Following this, permission to access the Community Health Index (CHI), which holds basic information on all residents registered with a GP within the health board, was sought and granted. Access to the deaths register from 1984 to the commencement of the study was also achieved.

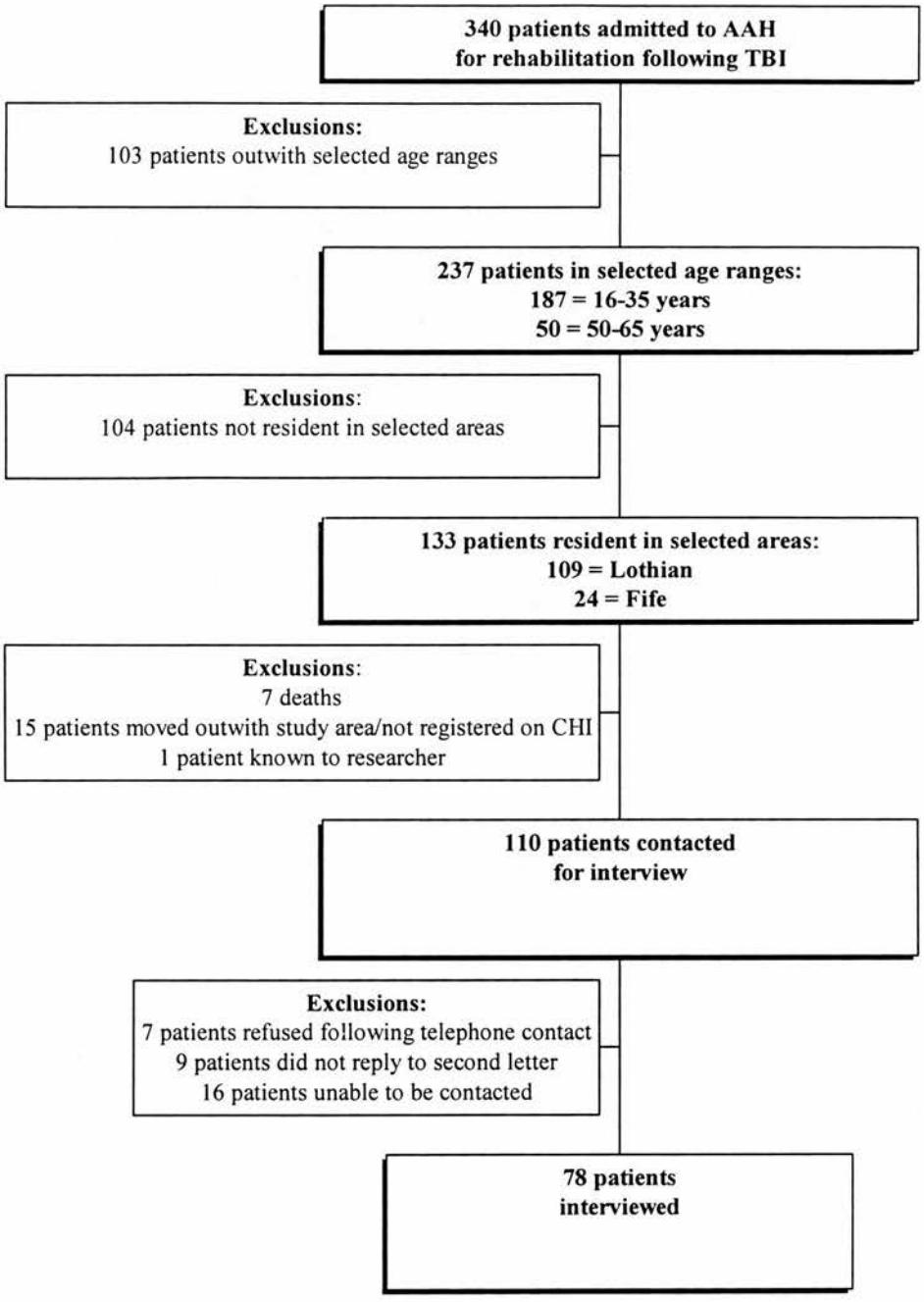
STUDY DESIGN

The study was a retrospective cohort study of TBI patients admitted to the Scottish Brain Injury Rehabilitation Service, based at the Astley Ainslie Hospital (AAH), Edinburgh.

STUDY POPULATION

The study population comprised individuals within a specified age range (16-35 years or 50-65 years), who had suffered a TBI over a seven year period, and had subsequently received rehabilitation at the AAH. The process of study population selection is described in the following section and is illustrated in Figure 4.1.

Figure 4.1 Inclusion and exclusion criteria

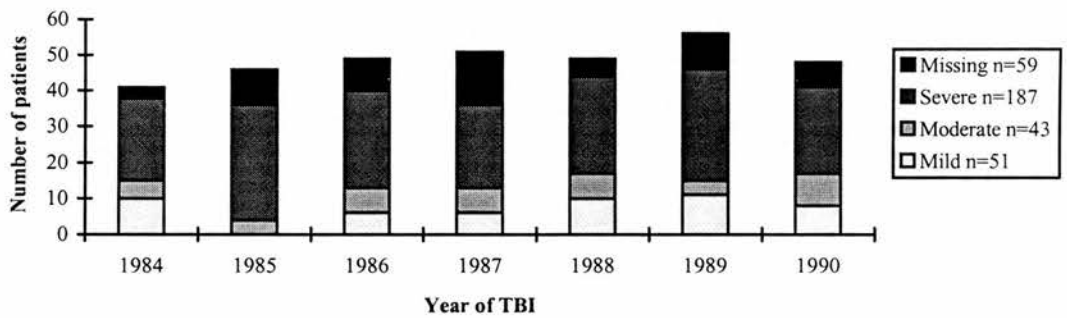


Details of Traumatic Brain Injury: year and severity

The sample was drawn from the total number of TBI admissions to the AAH between 1984-1990. Both male and female patients were included, irrespective of cause or injury severity. The majority of patients (60%) had been managed acutely at the Royal Infirmary of Edinburgh (RIE) prior to transfer to the AAH.

The starting point for the recruitment of patients was 1984, and as the focus of the study was long term assessment, 1990 was chosen as the end point. The study was carried out in 1995 giving a minimum of five years between injury and assessment. The number of TBI admissions to the AAH over the time period 1984-1990 was 340 (Figure 4.2). The majority of patients admitted for rehabilitation had sustained a severe TBI, based on GCS scores, with smaller numbers of moderate and mild injuries.

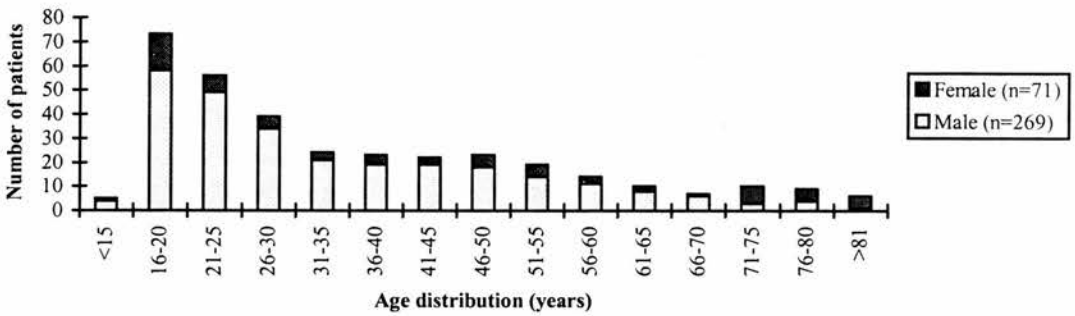
Figure 4.2 Severity of TBI admissions to AAH, from 1984-1990 (n=340)



Patient characteristics: age and area of residence

Figure 4.3 illustrates the age distribution of patients admitted to the AAH for rehabilitation following TBI, between 1984-1990. The median age was 30.5 years (mean=36.7, SD=18.4, range=13-92). Two age groups of patients, which tend to cover the peak incidences of TBI in adults, were selected for inclusion in this study: those aged 16-35 years or 50-65 years at the time of injury. One hundred and eighty seven patients fell into the younger age group and 50 into the older group, combining to cover 70% of admissions.

Figure 4.3 Age distribution of TBI admissions to AAH from 1984-1990 (n=340)



In order to limit travelling time for interviews, and to assist patient tracing, residence in either Lothian or Fife region (population of approximately 1 million) at the time of injury and interview, was required. As illustrated in Table 4.1, 179 patients were from Lothian and 30 from Fife, covering 61% of all admissions.

Table 4.1 Residence of TBI patients admitted to AAH from 1984-1990 (n=340)

Health Board	n (%)	Health Board	n (%)
Lothian	179 (52.6)	Grampian	8 (2.4)
Fife	30 (8.8)	Lanarkshire	8 (2.4)
Forth Valley	27 (7.9)	Islands	8 (2.4)
Greater Glasgow	19 (5.6)	Dumfries & Galloway	5 (1.5)
Ayrshire & Arran	13 (3.4)	Argyle & Clyde	4 (1.2)
Borders	13 (3.8)	Tayside	2 (0.6)
Highland	12 (3.5)	Missing	12 (3.5)

When the two criteria of age and residence are combined, 133 patients are eligible for inclusion in the study as illustrated in Table 4.2.

Table 4.2 Patients meeting age and area of residence criteria

	Lothian	Fife
Age (years)	n	n
16-35	74	24
50-65	35	0
Total	109	24

Approval from General Practitioner and rehabilitation consultant

Inclusion in the study required that the patient was registered with a GP. Access to the Community Health Index (CHI) allowed verification of the patient's name, address, date of birth and GP. The Rehabilitation Consultant and GP were contacted concerning their patient's proposed inclusion in the study and to seek their approval. This also provided an opportunity to inquire about any contra-indications to involvement in the study.

Exclusions

Twenty-two of the 133 patients thought to be eligible for inclusion in the study were excluded following a search of the CHI and deaths register (Figure 4.1). One patient was known to the author and was therefore excluded.

PROCEDURE

Recruitment of subjects

Patients were initially contacted by letter explaining the purpose of the study (Appendix B). This was followed by a telephone call to determine whether they were willing to participate. If agreeable, a suitable time was set up for an interview in the patient's own home. If telephone contact with the patient was not possible, a further letter was sent asking whether he would like to be included in the study, and if so, to suggest suitable times for an interview. If there was no response to either letter, no further attempt was made to contact these patients and this was noted as a refusal to participate. However, if the original letter was returned 'addressee gone away', information from the CHI and GP was checked, and where possible, the patient re-contacted.

The 110 patients who were eligible for inclusion in the study were approached in the manner described above and 78 were subsequently interviewed. This gives a response rate of 71%. The remaining 32 were not interviewed either because they refused to take part, did not respond to letters or it was not possible to contact them (Figure 4.1). No difference between responders and non-responders was found in terms of age or severity of injury.

Interview structure

The majority of the study data was collected by means of face-to-face interview with the patient using a variety of outcome measures. Where possible, and with the patient's agreement, a close relative or friend was also interviewed. Semi-structured interviews were conducted between February-August 1995 in the patient's own home, with the exception of five cases who were seen at the AAH. Following initial introductions, the author explained the purpose of the study in greater detail and the patient's written consent was gained. If the patient was unable to provide a signature, verbal consent was given and a family member was asked to sign on the patient's behalf.

Interview: Part one

The first part of the interview gathered information on the patient's personal and home situation, including marital status, living companions and employment or educational status, both prior to the injury and currently.

Interview: Part two

A number of outcome measures were completed by the interviewer or patient. The interviewer completed measures were the Glasgow Outcome Scale (GOS) (Jennett and Bond, 1975), the Functional Assessment Measure (FIM+FAM) (Keith et al. 1987; Hall et al. 1993) and the Edinburgh Rehabilitation Status Scale (ERSS) (Affleck et al. 1988). The self-report measures were the Short Form 36 (SF-36) (Ware and Sherbourne, 1992), the Functional Limitations Profile (FLP) (Bergner et al. 1976) and the Community Integration Questionnaire (CIQ) (Willer et al. 1993).

Interview: Part three

Where possible, an interview with an informant (either a close friend or relative of the patient) was also undertaken to provide supplementary information for assessment. In addition, the informant was asked to complete two questionnaires about the patient, the SF-36 and the Katz Adjustment Scale (KAS-R1) (Katz and Lyerly, 1963).

4.3 DESCRIPTION OF OUTCOME MEASURES

The outcome measures used in this study included a number which were specifically designed for use with TBI populations: GOS, FIM+FAM and the CIQ. Others have been developed for different populations but have previously been used in TBI studies such as the ERSS, FLP and KAS. At the time of the study, the SF-36 had not been reported in this population. There follows a brief description of each measure and the reasons behind its choice. They are divided into those completed by the author (= Interviewer completed measures); those the individual subject completed (= Self report measures) and those completed by the relative/principal carer (= Relative/carer completed measures).

INTERVIEWER COMPLETED MEASURES

Glasgow Outcome Scale

The Glasgow Outcome Scale (GOS) was developed by Jennett and Bond (1975) in order to assess the degree of permanent disablement requiring continued social support (Table 4.3). It is widely accepted as a measure of outcome following TBI and is recommended in all studies (Clifton et al. 1992). The GOS is a five level scale from 'Dead' to 'Good Recovery' which has been shown to have good inter-rater reliability (Jennett et al. 1981). However because of the limited number of categories, it is known to be insensitive to change (Wade, 1992b).

Table 4.3 Glasgow Outcome Scale

Category (score)	Description
Dead (1)	
Persistent Vegetative State (2)	Non-sentient; Not obeying commands; No verbal response; No meaningful response; May have sleep-wake rhythm; May have spontaneous eye opening and ability to follow moving objects; May swallow food.
Severe Disability (3)	Conscious and dependent requiring the help of another person at some time during every 24 hours. Disability may be mental and/or physical.
Moderate Disability (4)	Independent, i.e. can dress, make a meal, travel on public. transport. Some patients may work but at a reduced level.
Good Recovery (5)	Potentially able to return to work (although may be unemployed). May have some personality change, anosmia, mild dysphasia, trivial residual hemiparesis or cranial nerve palsy.

Functional Assessment Measure

The Functional Assessment Measure (FIM+FAM) is a 30-item measurement tool, designed for use by professionals of all rehabilitation disciplines involved in the care of brain injured patients (Hall et al. 1993). It has previously been discussed in Chapter Three, but for completeness it is also included here. The FIM+FAM is an expanded version of an earlier measure, the Functional Independence Measure (FIM), which contained 18-items (Keith et al. 1987). It covers a broader range of activities than earlier disability measures, such as the Barthel Index (Mahoney and Barthel, 1965). The FIM+FAM was included in this study as a broad, interviewer completed instrument, developed specifically for brain injured patients.

Content and scoring

The 30 items of the FIM+FAM are illustrated in Table 4.4. All are scored on a seven-level ordinal scale where levels six and seven indicate independence and levels one to five indicate dependence on another individual (Table 4.5). Results can be displayed as a profile. An overall score is not calculated, but summary motor and cognitive scores may be reported. The instrument can be completed by a professional or a team of professionals.

Table 4.4 Functional Assessment Measure dimensions

Motor items	Cognitive items
Self Care	**Communication**
Swallowing	Comprehension
Feeding	Expression
Grooming	Reading
Bathing	Writing
Dressing (upper)	Speech Intelligibility
Dressing (lower)	
Toileting	**Cognitive Function**
Bladder	Problem Solving
Bowel	Memory
	Orientation
Mobility	Attention
Bed/Chair Transfers	Safety Judgement
Toilet Transfers	
Bath Transfers	**Psychosocial**
Car Transfers	Social Interaction
Locomotion	Emotion
Stairs	Adjustment to Limits
Community Mobility	Employability

Table 4.5 Functional Assessment Measure scoring

	Score	Description
Independent	7	Complete independence
	6	Modified independence
Dependent	5	Supervision or set up
	4	Minimal contact assistance
	3	Moderate assistance
	2	Maximal assistance
	1	Total assistance

Reliability and validity

Although there is evidence for the reliability and validity of the FIM (Dodds et al. 1993; Hamilton, 1994), only a few studies have looked at the FIM+FAM (Ditunno, 1992; Frattali, 1993; McPherson et al. 1996). Fratalli (1993) reported that preliminary work had demonstrated that the FIM+FAM had face validity, and concurrent validity with clinical observations, the DRS (Rappaport et al. 1982), the Barthel Index (Wade and Collin, 1988) and the FIM. A study by McPherson et al. (1997) provided some support for the content validity of the FIM+FAM in measuring cognitive disability. A study involving the author, found that there was good inter-rater reliability for 29 of the 30 items in the FIM+FAM, although higher agreement was noted for the physical activities than for the cognitive, communication or behavioural items (McPherson et al. 1996).

Edinburgh Rehabilitation Status Scale

The Edinburgh Rehabilitation Status Scale (ERSS) was designed as a global outcome scale, to measure medicosocial dysfunction in individuals or groups with a disabling illness or during rehabilitation (Affleck et al. 1988). The ERSS was included in this study as an interviewer-rated, global outcome measure designed for use in a rehabilitation setting (Appendix B).

Content and scoring

The four subscales which constitute the ERSS are presented in Table 4.6.

Table 4.6 ERSS subscales

ERSS subscale	Description
Independence/Dependence (SUPP)	Frequency of the acceptance of support, and the reliance on others for self-care, and extended ADL.
Activity/Inactivity (INACT)	Ability to initiate and perform the physical and cognitive activities required for his/her occupation, home life and leisure activities.
Social Integration/Isolation (ISOL)	Involvement with others, including the extent and quality of social and domestic participation.
Effect of Symptoms on Lifestyle (EFFSYM)	Frequency and severity of symptoms and the problems that they cause.

Rating is usually possible from the routinely collected data based on the previous week, although additional information from other professionals or relatives may be used if necessary. It should take around five minutes to complete if the patient is known to the rater. Each subscale is graded on an equivalent scale from 0-7 (Table 4.7) and a total score can be calculated. Higher scores indicate greater severity of need and results can be presented as a profile. The total score can be categorised as follows: 0-8 (high level of functioning); 9-16 (medium level of functioning); 17-28 (low level of functioning).

Table 4.7 ERSS scoring

Description	Score
No abnormality in this dimension	0
Intermittent minor problems	1
Intermediate grade	2
Impairment, disability or handicap is noticeable to friends or relatives	3
Intermediate grade	4
Impairment, disability or handicap is obvious to the 'man in the street'	5
Intermediate grade	6
Extreme degree of impairment, disability or handicap	7

The ERSS manual states that a patient who

> 'scores four or less is unlikely to require a multi-professional rehabilitation programme although further treatment for their impairment may be required. If the patient in the community has an ERSS score above 12 it is likely that he or she will have difficulty maintaining even sheltered employment'.
>
> (Affleck and McGuire, 1993)

Reliability and validity

The ERSS has been shown to have acceptable inter-rater reliability and be sensitive to change (Affleck et al. 1988). Mattison et al. (1989) found reasonably strong correlations between total scores on the ERSS, PULSES profile (Granger et al. 1979) and Barthel Index with weaker correlations between some of the individual subscales, indicating the different dimensions of disability and handicap being addressed. The ERSS was found to correlate well with hours of care required in a population with neurological disabilities (Disler et al. 1993). However there are few published papers to fully establish the validity of the ERSS (Roy, 1991). Use of the measure has been previously reported in a TBI population and was

found to provide a general picture of the patient but was relatively insensitive to change (Gray et al. 1994; Anderson et al. 1996).

SELF REPORT MEASURES

Short Form 36

In recent years the need for shorter, generic outcome measures has been emphasised (Katz et al. 1992). Such tools are required to help fill the gap between the longer measures often used in research projects, such as the Sickness Impact Profile (SIP) (Bergner et al. 1976), and the coarse single item measures which have been employed in some surveys and clinical settings (Spitzer et al. 1981). Shorter measures should also help to reduce the burden on the respondent, increase the response rate and may encourage the routine collection of outcome data in the clinical setting (Ellwood, 1988).

One such short, generic measure which has been developed is the Short Form 36 (SF-36). The SF-36 represents a carefully chosen selection of items from the larger Medical Outcomes Study (MOS), including the most frequently used health concepts from previous health surveys. It was designed to reproduce the parent MOS scale as closely as possible (Ware and Sherbourne, 1992; McHorney et al. 1993) and was made up of the items using factor analysis of 149 items from the longer scales. The SF-36 was designed for self completion or to be used as part of a face-to-face or telephone interview. It takes around 5-10 minutes to complete. An anglicised version of the SF-36 was developed by a team in Sheffield (Brazier and Jones, 1992) and population norms are available for the UK (Garratt et al. 1993; Jenkinson et al. 1993).

The SF-36 was included in this study as a self report health status assessment instrument which has been widely used in many populations over recent years.

Content and scoring

The SF-36 was so called because it has 36 multiple-choice questions all of which require the subject to respond by ticking a box. The items can be aggregated in to the eight scales shown in Table 4.8. Each scale has a specific response format which ranges from 'yes/no' responses to six point scales.

Table 4.8 Number of items in each SF-36 scale

SF-36 scale	Number of items
Physical Functioning (PF)	10
Physical Role Limitations (RP)	4
Bodily Pain (BP)	2
General Health Perceptions (GH)	5
Vitality (VT)	4
Social Functioning (SF)	2
Emotional Role Limitations (RE)	3
General Mental Health (MH)	5
Total	35*

*36th item asks patient to compare present health with that one year before and is not included within the eight scales

Items require to be re-coded prior to summation into the eight dimensions which are then transformed, using a scoring algorithm, into a scale from 0-100 (Ware et al. 1993). A higher score indicates better health and results can be displayed as a profile (Ware and Sherbourne, 1992).

Reliability and validity

The UK version of the SF-36 has been shown to be acceptable to patients, with good test-retest properties (Brazier and Jones, 1992) and high internal consistency (Jenkinson et al. 1993). Garratt et al. (1993) found that the SF-36 satisfied rigorous psychometric criteria for validity and internal consistency in a postal survey of patients with one of four common conditions. This Aberdeen based research group also found that the SF-36 had high reliability (Ruta et al. 1994) and was responsive to change in a patient population (Garratt et al. 1993). Responsiveness to change in health status was confirmed in the general population by Hemingway et al. (1997). The SF-36 is thought to be more sensitive for those with low levels of perceived ill-health than some other measures such as the Euroqol (Brazier et al. 1993). The SF-36 has however been criticised by Hunt and McKenna (1993) who felt that the developers have relied too much on psychometric techniques when designing and testing the SF-36.

Functional Limitations Profile

The Functional Limitations Profile (FLP) is the UK version of the more commonly used Sickness Impact Profile (SIP). The FLP/SIP is a self-report measure of sickness-related dysfunction. It was developed in the 1970's as a means of measuring perceived health status, focusing on changes in an individual's behaviour due to illness (Bergner et al. 1976). It was designed for use with all types of patients with varying disease severity. The SIP, or a modified version, has been used with a TBI population in a number of studies (Klonoff et al. 1986; Temkin et al. 1988; Temkin et al. 1989; Van Balen and Mulder, 1996).

The FLP/SIP was designed as a self-report tool but can also be administered by means of an interview (Smith, 1992). Subjects only tick items within each category that they feel describe them and are related to their health and it is estimated that it takes 15-35 minutes to complete. The FLP/SIP was included in this study as a well respected self report measure designed to assess the perceived health status of the patient.

Content and scoring

The FLP/SIP contains 136 statements on physical, social and cognitive functioning and emotional well-being which describe behaviours and the extent to which they limit the individual. The statements are divided into 12 subscales, nine of which can be aggregated into two dimensions, Physical and Psychosocial (Table 4.9). The 136 statements can be summed to produce 12 category scores, two dimension scores (Physical and Psychosocial) and an overall score with a range of 0-100. A lower score indicates better health.

Table 4.9 FLP/SIP subscales

Physical Dimension	Psychosocial Dimension	Other subscales
Ambulation (AM)	Social Interaction (SI)	Communication (CM)
Body Care (BC)	Emotion (EM)	Eating (EAT)
Mobility (MB)	Alertness (AL)	Work (WK)
Household Management (HM)	Sleep & Rest (S&R)	
	Recreation (RC)	

Reliability and validity

The SIP has been shown to be reliable, valid and responsive in a number of settings (Pollard et al. 1976; Read et al. 1987; Brooks et al. 1990; Katz et al. 1992). McDowell and Newell (1987) concluded that the SIP was developed with 'exemplary care and thoroughness' and suggested that it would become the standard against which to evaluate other health measures. There are doubts however as to whether the SIP is able to measure change in patient function (Smith, 1992; Schuling et al. 1993).

Klonoff et al. (1986) assessed the quality of life 2-4 years after TBI (n=78) using the original SIP and the Katz Adjustment Scale (Katz and Lyerly, 1963). She found that the SIP results were generally in agreement with interview data and reports from relatives. The SIP has been modified by researchers in various ways. Bruin et al. (1994), developed a shortened measure (SIP-68) by extracting 68 items from the various subscales and its validity and reliability has been partially established (Bruin et al. 1994; Post et al. 1996). Temkin et al. (1989) modified the SIP for use with a TBI population by adding and removing items and reweighting item values. However this version was no more sensitive than the original SIP to TBI related changes.

The UK version of the SIP, the FLP, is very similar to the original but has linguistic changes and the scale weights have been re-calculated (Charlton et al. 1983). The reliability and validity of the FLP has been less extensively evaluated than the SIP.

Community Integration Questionnaire

This measure was developed specifically for the TBI population to measure handicap in the community (Appendix B). Return to home and integration into the community is seen as an important goal of rehabilitation, particularly as the majority of victims are young adults (Willer et al. 1993; Willer et al. 1994). The CIQ was included in this research to assess re-integration into the community but was only introduced midway through the study.

Content and scoring

The CIQ contains 15 items which are grouped into three subscales (Table 4.10).

Table 4.10 CIQ subscales

CIQ subscale	Description	Score
Home Integration	Domestic activities, housework, caring for children, shopping.	0-10
Social Integration	Visiting friends, participating in leisure activities with others.	0-12
Productivity	School, work, voluntary work and the use of transportation.	0-7

The CIQ can be self-administered or used as part of a face-to-face or telephone interview taking around 10-15 minutes to complete. Three subscale scores (Home Integration, Social Integration and Productivity) and an overall score (range 0-29) can be calculated. A low score indicates poor integration.

Reliability and validity

The CIQ was shown to have acceptable test-retest reliability, although the inter-rater reliability is yet to be fully established (Willer et al. 1994). Good agreement was also found between the survivor and a family member and the CIQ was able to discriminate between TBI patients and controls. The CIQ is thought to be a useful and simple measure of community integration and handicap for the TBI population (Corrigan and Deming, 1995).

RELATIVE/CARER COMPLETED MEASURES

Short Form 36

A slightly modified version of the SF-36 was completed by asking relatives to report on the patient's health status.

Katz Adjustment Scale - Relatives Questionnaire

Initially devised by Katz and Lyerly (1963) for use with psychiatric patients, the Katz Adjustment Scale (KAS) has been cited as having some utility in assessing neurobehavioural functioning following TBI (Prigatano and Fordyce, 1986). The KAS has five sections and it is the first of these (KAS-R1) which has received most attention, and is used in this study to record the patient's previous and current neurobehavioural functioning, from the perspective of the relative.

Content and scoring

The KAS-R1 contains 127 items covering numerous psychological, emotional and behavioural characteristics which are rated on a four point scale by a significant other. The results of factor analysis by the originators yielded 12 clusters (Belligerence, Verbal Expansiveness, Negativism, Helplessness, Suspiciousness, Anxiety, Withdrawal and Retardation, General Psychopathology, Nervousness, Confusion, Bizarreness and Hyperactivity) which were found to be have internal consistency and have stable relationships amongst clusters (Katz and Lyerly, 1963).

Reliability and validity

The KAS-R1 may be a useful means of assessing neurobehavioural function and personality in the TBI population as it covers a wide range of social and emotional behaviour and psychiatric items, many of which ask for ratings of overt behaviour. It has proven discriminative validity with well adjusted and poorly adjusted patients (Jackson et al. 1992) and comparative data is available for psychiatric and normal populations (Hogarty and Katz, 1971). In its original form, however, the KAS-R1 does not allow evaluation of change and the factor structure was devised from a psychiatric rather than a TBI population (Jackson et al. 1992).

To a certain extent, these problems have been addressed with researchers utilising the KAS-R1 with a TBI population, and analysing their results to produce different component groups

(Fabiano and Goran, 1992; Jackson et al. 1992). Jackson et al. (1992) included both TBI and spinal cord patients in their study and they suggested that a pre-injury rating also be included in order to evaluate change. Goran and Fabiano (1993) have attempted to increase the utility of the KAS-R1 following TBI and have reduced the number of items from 127 to 79. The 79 items have been analysed to produce ten component subscales, some of which have increased levels of internal consistency (Fabiano and Goran, 1992; Goran and Fabiano, 1993). This shortened version, using pre and post-injury scores, is used in this study.

4.4 PILOT STUDY

A pilot study was carried out using a selection of outcome measures in order to determine those most appropriate for use some years post-injury. This involved 15 patients, who were not included in the main study, the majority of whom were community based. The pilot study found that the chosen measures were generally acceptable to the sample and could be completed within the allotted time period.

4.5 SUMMARY

This chapter has described the study population (n=78) and methods used in a long term follow up study of TBI, where the main form of data collection is by face-to-face interview. The sample was drawn from TBI admissions to a rehabilitation unit in Edinburgh between 1984-1990. Patients were aged between 16-35 years or 50-65 years at the time of TBI and were resident in Lothian or Fife. The process of contacting patients and the interview structure has been detailed. The selected outcome measures have been grouped into interviewer completed, self-report and relative/carer completed measures. Their content, scoring, reliability and validity have been described.

Chapter Five

Long term follow up of traumatically brain injured individuals by interview: Results

5.1 INTRODUCTION

This chapter provides the results of the interview study of TBI patients 5-11 years after injury and follows the same structure as Chapter Four. Demographic and patient data including age, sex, area of residence, occupational and marital status are presented. Details of TBI severity, cause and associated injuries are provided. This is followed by results of the patient's functional status and well being, captured by the interviewer completed, self report and relative/carer completed outcome measures.

5.2 DEMOGRAPHIC AND PATIENT DATA

AGE, SEX AND AREA OF RESIDENCE

Of the 78 patients who participated in the study, 60 were male (77%) and 18 were female (23%), giving a male to female ratio of 3.3:1.0. The patients were selected to fall into two age categories at the time of injury (younger group = 16-35 years and older group = 50-65 years) as illustrated in Table 5.1. Over 70% of patients were in the younger age group.

Table 5.1 Age, sex and area of residence of interview sample

	16-35 yr olds (n=57)	50-65 yr olds (n=21)
Age at injury (years)		
Mean (SD)	24 (5)	57 (4)
Median	22	56
Range	17-35	50-65
Age at follow up (years)		
Mean (SD)	32 (5)	65 (5)
Median	30	65
Range	24-43	55-73
Sex		
Male	45	15
Female	12	6
Area of residence		
Lothian	46	21
Fife	11	0

OCCUPATIONAL STATUS

At the time of the TBI, 81% of the sample were working but this had reduced to only 24% at by follow up (Table 5.2). The figures for the younger age group are similar with 79% employed pre-injury and 33% post-injury. However, the effect of the TBI on the occupational status of the older population is more difficult to interpret as many of this group had reached retiral age during the period of follow up. The majority of patients included in the 'Other' category were in education.

Table 5.2 Occupational status, by age group, at injury and follow up

	16-35 yr olds (n=57)		**50-65 yr olds (n=21)**		**Total (n=78)**	
Occupational	Injury	Follow up	Injury	Follow up	Injury	Follow up
Status	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Working	45 (79)	19 (33)	18 (86)	0 (0)	63 (81)	19 (24)
Retired	0 (0)	0 (0)	1 (5)	7 (33)	1 (1)	7 (9)
Unemployed	5 (9)	36 (63)	1 (5)	14 (67)	6 (8)	50 (64)
Other	7 (12)	2 (4)	1 (5)	0 (0)	8 (10)	2 (3)

At injury, one of the unemployed patients attended a Day Centre and by follow up this figure had risen to 12 with a further three undertaking voluntary work.

MARITAL STATUS AND LIVING ARRANGEMENTS

There were changes in marital status between injury and follow up, particularly in the younger age group with more patients cohabiting or divorced (Table 5.3). However, it is not possible to determine whether this was due to the injury or if these changes would have occurred despite the TBI. Associated with the changes in marital status were alterations in living arrangements (Table 5.3). The 'Other' category included those in hostels, student flats, sheltered accommodation, the armed forces or of no fixed abode.

Table 5.3 Marital status and living arrangements at injury and follow up

	16-35 yr olds (n=57)		50-65 yr olds (n=21)	
	Injury n (%)	Follow up n (%)	Injury n (%)	Follow up n (%)
Marital status				
Single	42 (74)	31 (54)	3 (14)	3 (14)
Married	12 (21)	14 (25)	13 (62)	12 (57)
Cohabiting	1 (2)	6 (11)	0 (0)	0 (0)
Divorced/Separated	2 (4)	6 (11)	4 (19)	5 (24)
Widowed	0 (0)	0 (0)	1 (5)	1 (5)
Living arrangements				
Alone	10 (18)	13 (23)	8 (38)	7 (33)
With spouse/partner	12 (21)	18 (32)	13 (62)	12 (57)
With parents/family	31 (54)	22 (39)	0 (0)	1 (0.5)
Other	4 (7)	4 (7)	0 (0)	1 (0.5)

INJURY DETAILS

TIME POST-INJURY

Interviews were carried out 5-11 years after injury providing a total of 614 person-years of follow up. The mean number of years of follow up was eight for both age groups. No difference was found between the severity of TBI and the number of years of follow up (Kruskal Wallis H = 2.373, p=0.305).

INJURY SEVERITY

The severity of TBI was described by GCS score as unfortunately PTA data was available for only a minority of patients. In order to ensure accuracy and consistency when collecting GCS data, the following guidelines were applied where possible:

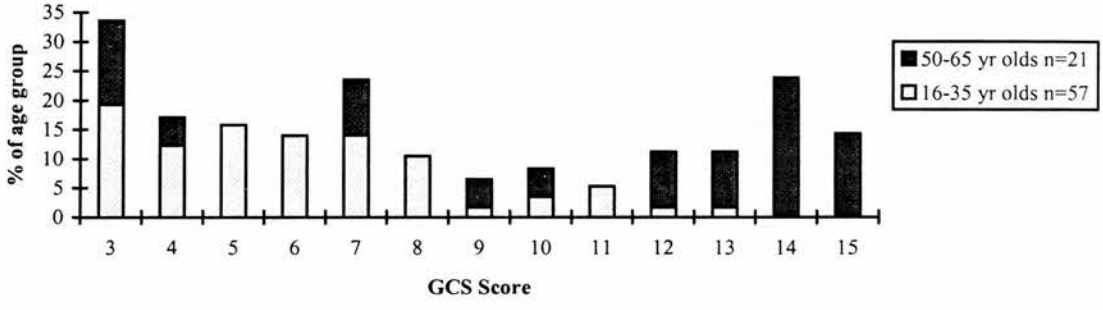
- clinical notes were used to determine the GCS score rather than using the overall score quoted in the discharge summary;
- the GCS score at six hours post-injury was used, and a pre-surgery or pre-intubation score was taken if necessary. Any deterioration in the first 24 hours after injury was noted, and this reduced the GCS score in four cases (Johnston and Hall, 1994).

The severity of TBI was categorised by the GCS score as follows: mild (GCS 13-15); moderate (GCS 9-12); severe (GCS 3-8) (Rimel et al. 1981; Rimel et al. 1982). In accordance with recent research, individuals with a GCS of 13-15 but requiring neurosurgical evacuation of a haematoma were categorised as moderate, rather than mild, brain injuries (Gomez et al. 1996). In this study, only one patient fell into this group. Table 5.4 and Figure 5.1 illustrate the severity of TBI by age group and reveal that the majority of injuries were classified as severe. The younger sample tended to have had the most severe injuries, with 86% classified as severe TBIs compared with 29% of the older sample. In contrast, only 2% of the younger group had a mild injury compared with 43% of the older group. This difference in injury severity between the age groups was confirmed by a Mann-Whitney test (U= 227.0, p<0.001).

Table 5.4 Severity of TBI by age group

	16-35 yr olds (n=57)	50-65 yr olds (n=21)	Total (n=78)
Severity of TBI	n (%)	n (%)	n (%)
Mild (GCS 13-15)	1 (2)	9 (43)	10 (13)
Moderate (GCS 9-12)	7 (12)	5 (24)	12 (15)
Severe (GCS 3-8)	49 (86)	6 (29)	55 (71)
Unknown	0 (0)	1 (5)	1 (1)

Figure 5.1 GCS score by age group (n=78)



CAUSE OF INJURY

Half of all the TBIs in this sample were due to road traffic accidents (RTAs), the majority of which were pedestrian injuries (Table 5.5). The second most common cause was falls and the remainder were due to either assaults, or work-related or sporting accidents. When comparing the two age groups, it is noted that RTAs were much more common in the younger sample (63% of all injuries), whereas falls were the most prevalent cause in the older sample (62% of all injuries). To determine the statistical relationship between age and cause, injuries were grouped into three categories (RTAs, Falls and Other), and a chi-square test revealed a highly significant relationship (χ^2=15.25 $p<0.001$). This result is supported by the data relating to injury severity and age, which showed that more severe injuries occur in the younger age group who also tend to be involved in RTAs.

Table 5.5 Cause of TBI by age group

	16-35 yr olds (n=57)	**50-65 yr olds (n=21)**	**Total (n=78)**
Cause	n (%)	n (%)	n (%)
RTA - Driver	6 (11)	0 (0)	6 (8)
RTA - Passenger	10 (18)	1 (5)	11 (14)
RTA - Pedestrian	14 (25)	2 (10)	16 (21)
RTA - Motorbike	6 (11)	0 (0)	6 (8)
Falls	13 (23)	13 (62)	26 (33)
Assaults	4 (7)	3 (14)	7 (9)
Work Accident	2 (4)	2 (10)	4 (5)
Sport/Recreation	2 (4)	0 (0)	2 (3)

INJURIES TO THE SKULL AND BRAIN AND NEUROSURGERY

Table 5.6 describes the major injuries to the skull and brain and need for neurosurgical intervention. More than half of the patients had sustained a skull fracture, the most common of which was to the vault of the skull. Ten percent had both vault and basal fractures. It is interesting to note that vault fractures were much more common in the older age group and this may relate to the higher proportion of contact injuries (i.e. falls) compared with acceleration/deceleration injuries (i.e. RTAs) in this group.

Table 5.6 Skull fractures, intracranial lesions and neurosurgery

	16-35 yr olds (n=57)	50-65 yr olds (n=21)	Total (n=78)
	n (%)	n (%)	n (%)
Skull fracture			
Any fracture	28 (49)	15 (71)	43 (55)
Vault fracture	24 (42)	15 (71)	39 (50)
Basal fracture	9 (16)	3 (14)	12 (15)
Intracranial lesions			
Contusion	24 (42)	9 (43)	33 (42)
Intracranial haematoma	19 (33)	9 (43)	28 (36)
Subdural haematoma	8 (14)	5 (24)	13 (17)
Extradural haematoma	5 (9)	1 (5)	6 (8)
Intracerebral haematoma	7 (12)	4 (19)	11 (14)
Diffuse axonal injury	32 (56)	3 (14)	35 (45)
Neurosurgical operation			
Evacuation of haematoma	12 (21)	4 (19)	16 (21)
Polectomy/lobectomy	3 (5)	1 (5)	4 (5)
Elevation of skull fracture	5 (9)	0 (0)	5 (6)
Insertion of ICP monitor	35 (61)	5 (24)	40 (51)
No neurosurgery†	40 (70)	17 (81)	57 (73)

† No neurosurgery or insertion of ICP monitor only

Fifty-three patients had sustained focal intracranial damage either in the form of a contusion and/or intracranial haematoma (Table 5.6). Subdural and intracerebral haematomas were particularly common in the older age group and this may relate to the increasing fragility of vessels with age. The diagnosis of diffuse axonal injury (DAI) was based on a coma of at least six hours duration, plus either a normal CT scan or a CT scan which did not reveal an

SDH, EDH, ICH or contusion causing a pressure effect (Gennarelli et al. 1982a). Thirty five patients met the criteria for DAI, the majority of whom were in the younger age group. This again corresponds with the greater severity of injury and higher frequency of RTAs in this younger group. The most common form of neurosurgery was the evacuation of a haematoma which was undertaken in a fifth of each group. Seventy percent of the younger group and 80% of the older group did not require any neurosurgical intervention or had only the insertion of an ICP monitor.

EXTRACRANIAL INJURIES

Table 5.7 illustrates the major extracranial injuries sustained in each age group and need for subsequent surgery. It is noted that orthopaedic and abdominal injuries and subsequent surgery were more common in the younger population. This probably relates to the frequency of RTAs which may be associated with multiple injuries.

Table 5.7 Site of extracranial injuries and surgical intervention

	16-35 yr olds (n=57)		50-65 yr olds (n=21)	
Site of injury	n (%)	Surgery (%)	n (%)	Surgery (%)
Orthopaedic	21 (37)	5 (9)	5 (24)	0 (0)
Abdominal	6 (11)	6 (11)	0 (0)	0 (0)
Facial	5 (9)	2 (4)	2 (10)	1 (5)
Spinal	1 (2)	0 (0)	0 (0)	0 (0)
Other	3 (5)	1 (2)	1 (5)	1 (5)

5.3 OUTCOME MEASURES

On average, interviews took between 60-90 minutes to complete and all were undertaken by the author. Results are discussed with regard to three main factors, age, severity of TBI and time post-injury. Because of the number of comparisons undertaken in the analysis, only results significant at $p<0.01$ or $p<0.001$ level will be discussed.

5.3.1 INTERVIEWER COMPLETED MEASURES

Glasgow Outcome Scale

Patients were rated by the author on the GOS (Table 5.8). Only three of the five outcome categories were required as no patients were in a persistent vegetative state or had died. Over half the patients had made a good recovery (i.e. were capable of resuming normal occupational or social activities), a third had moderate disability (i.e. were independent but disabled) and the remainder had severe disability (i.e. required the assistance of another person each day). Dividing the results by age revealed that half of each age group had made a good recovery. A Mann-Whitney test revealed no significant difference in GOS score between the age groups ($U = 586.50$, $p=0.881$), and this result is surprising bearing in mind the difference in initial injury severity.

Table 5.8 also illustrates the GOS score by severity of TBI and shows that patients who had sustained a severe TBI tended to have a poorer outcome. However, a Kruskal Wallis test revealed that there was no significant difference in GOS score between the severity groups ($H=4.50$, $p=0.105$) or relating to time post-injury ($H=10.00$, $p=0.124$).

Table 5.8 GOS category by age group and severity of TBI

	Severe Disability	Moderate Disability	Good Recovery
	n (%)	n (%)	n (%)
Age group			
16-35 yr olds (n=57)	7 (12)	21 (37)	29 (51)
50-65 yr olds (n=21)	4 (19)	6 (29)	11 (52)
Severity group			
Mild (n=10)	0 (0)	4 (40)	6 (60)
Moderate (n=12)	1 (8)	2 (17)	9 (75)
Severe (n=55)	10 (18)	21 (38)	24 (44)
Total sample (n=78)	11 (14)	27 (35)	40 (51)

As severity of the TBI sustained has been shown to be significantly different between the age groups, the GOS results have been further examined in order to explore this relationship. Kendall partial correlations, which allow a factor such as age to be controlled for, were undertaken. Results showed that the association between GOS score (x) and severity of TBI (y) was very weak ($T_{xy} = 0.110$) and that controlling for age (z) had only a slight effect on the correlation ($T_{xy.z} = 0.126$).

Functional Assessment Measure

The FIM+FAM measures level of dependence on a seven-level ordinal scale with a higher score indicating better functioning.

Functional Assessment Measure scores

Table 5.9 presents data for the 30 items of the FIM+FAM and all, except Emotion and Employability, have median scores of six or seven indicating independence.

Table 5.9 Functional Assessment Measure scores (n=78)

Dimension	Mean (SD)	Median	Dimension	Mean (SD)	Median
Self Care			**Communication**		
Swallowing	7.0 (0.2)	7.0	Comprehension	6.1 (1.1)	6.0
Feeding	6.8 (0.6)	7.0	Expression	6.0 (1.1)	6.0
Grooming	6.6 (0.8)	7.0	Reading	5.8 (1.0)	6.0
Bathing	6.7 (0.8)	7.0	Writing	5.8 (1.4)	6.0
Dressing (upper)	6.5 (1.0)	7.0	Speech Intelligibility	6.2 (1.2)	7.0
Dressing (lower)	6.4 (1.0)	7.0			
Toileting	6.8 (0.8)	7.0	**Cognition**		
Bladder	6.8 (0.9)	7.0	Problem Solving	5.6 (1.3)	6.0
Bowel Care	7.0 (0.1)	7.0	Memory	5.3 (1.4)	6.0
			Orientation	6.1 (1.1)	6.0
Mobility			Attention	5.5 (1.4)	6.0
Bed Transfers	6.7 (0.6)	7.0	Safety Judgement	5.9 (1.1)	6.0
Toilet Transfers	6.7 (0.6)	7.0			
Bath Transfers	6.5 (0.8)	7.0	**Psychosocial**		
Car Transfers	6.6 (0.9)	7.0	Social Interaction	5.8 (1.3)	6.0
Locomotion	6.4 (0.8)	6.0	Emotion	5.2 (1.5)	5.5
Stairs	6.1 (1.5)	6.0	Adjustment to Limits	5.7 (1.4)	6.0
Community Mobility	5.7 (1.4)	6.0	Employability	5.3 (1.2)	5.0

Summary scores for the 16 Motor items (range 16-112) and 14 Cognitive items (range 14-98) were also calculated (Table 5.10). No significant differences were found in the summary scores for the two age groups (Motor: U=477.0, p=0.161; Cognitive: U=540.5, p= 0.513), severity groups (Motor: H=0.675, p=0.714; Cognitive: H=1.86, p=0.394) or time since injury (Motor: H=8.07, p=0.233; Cognitive: H=9.39, p=0.153).

Table 5.10 Summary FIM+FAM scores by age group and severity of TBI

	Motor score		Cognitive score	
	Mean (SD)	Median	Mean (SD)	Median
Age group				
16-35 yr olds (n=57)	100.6 (6.8)	104.0	86.7 (14.6)	89.0
50-65 yr olds (n=21)	96.4 (13.8)	102.0	84.0 (17.3	86.0
Severity group				
Mild (n=10)	100.7 (6.1)	103.0	85.0 (20.3)	90.5
Moderate (n=12)	101.2 (6.1)	104.0	90.8 (12.5)	93.0
Severe (n=55)	98.8 (10.4)	102.0	84.8 (14.8)	88.0
Total sample (n=78)	99.5 (9.3)	103.0	86.0 (15.3)	88.5

Functional Assessment Measure by age group, severity of injury and time post-injury

Comparisons of each of the 30 items between the age groups, severity groups and time post-injury were undertaken, but no differences were found at the $p<0.01$ or $p<0.001$ level (Table 5.11 and 5.12).

Table 5.11 Differences in FIM+FAM Motor scores between age groups, severity of TBI and time post-injury (n=78)

Dimension	Age groups p (sig level†)	Severity of TBI p (sig level†)	Time post-injury p (sig level†)
Self Care			
Swallowing	0.459 (NS)	0.667 (NS)	0.690 (NS)
Feeding	0.423 (NS)	0.687 (NS)	0.349 (NS)
Grooming	0.502 (NS)	0.968 (NS)	0.199 (NS)
Bathing	0.088 (NS)	0.776 (NS)	0.318 (NS)
Dressing (upper)	0.946 (NS)	0.223 (NS)	0.369 (NS)
Dressing (lower)	0.717 (NS)	0.213 (NS)	0.187 (NS)
Toileting	0.374 (NS)	0.419 (NS)	0.269 (NS)
Bladder	0.026 (*)	0.147 (NS)	0.414 (NS)
Bowel Care	0.099 (NS)	0.819 (NS)	0.650 (NS)
Mobility			
Bed Transfers	0.055 (NS)	0.751 (NS)	0.022 (*)
Toilet Transfers	0.084 (NS)	0.917 (NS)	0.045 (*)
Bath Transfers	0.033 (*)	0.642 (NS)	0.055 (NS)
Car Transfers	0.106 (NS)	0.932 (NS)	0.061 (NS)
Locomotion	0.563 (NS)	0.283 (NS)	0.383 (NS)
Stairs	0.124 (NS)	0.934 (NS)	0.302 (NS)
Community Mobility	0.469 (NS)	0.694 (NS)	0.033 (*)

† NS=non-significant, *=$p<0.05$

Table 5.12 Differences in FIM+FAM Cognitive scores between age groups, severity of TBI and time post-injury (n=78)

Dimension	Age groups p (sig level†)	Severity of TBI p (sig level†)	Time post-injury p (sig level†)
Communication			
Comprehension	0.268 (NS)	0.577 (NS)	0.425 (NS)
Expression	0.496 (NS)	0.515 (NS)	0.634 (NS)
Reading	0.218 (NS)	0.511 (NS)	0.310 (NS)
Writing	0.022 (*)	0.608 (NS)	0.842 (NS)
Speech Intelligibility	0.740 (NS)	0.112 (NS)	0.582 (NS)
Cognition			
Problem Solving	0.682 (NS)	0.268 (NS)	0.204 (NS)
Memory	0.354 (NS)	0.210 (NS)	0.082 (NS)
Orientation	0.730 (NS)	0.302 (NS)	0.608 (NS)
Attention	0.564 (NS)	0.714 (NS)	0.092 (NS)
Safety Judgement	0.390 (NS)	0.864 (NS)	0.029 (*)
Psychosocial			
Social Interaction	0.887 (NS)	0.578 (NS)	0.375 (NS)
Emotion	0.977 (NS)	0.314 (NS)	0.525 (NS)
Adjustment to Limits	0.379 (NS)	0.958 (NS)	0.160 (NS)
Employability	0.577 (NS)	0.200 (NS)	0.104 (NS)

† NS=non-significant, *=$p<0.05$

In order to control for the effects of age, Kendall partial correlations between the FIM+FAM summary scores (x) and TBI severity (y) were undertaken (Table 5.13). The results reveal that age (z) had a greater effect on the Motor score than the Cognitive score, but the correlations remained very weak.

Table 5.13 Kendall partial correlations between FIM+FAM summary scores and severity of TBI (by GCS score) controlling for age at injury (n=78)

FIM+FAM	Correlation between FIM+FAM score and severity (T_{xy})	Partial correlation controlling for age ($T_{xy.z}$)
Motor score	0.121	0.184
Cognitive score	0.133	0.159

Distributional characteristics of Functional Assessment Measure

To determine whether the range of functional ability defined by the FIM+FAM was appropriate for the TBI population many years after injury, the percentage of the sample achieving lowest (floor effect) and highest (ceiling effect) scores were calculated (Tables 5.14 and 5.15). Although floor effects were not evident, very large ceiling effects were found across all the Motor and many of the Cognitive items indicating that no further improvement would be possible on this scale. These ceiling effects might have contributed to the lack of significant differences between the age, severity and time post-injury groups (Tables 5.11 and 5.12).

Table 5.14 Distributional characteristics of Motor FIM+FAM items (n=78)

	Floor	Ceiling	Range
Dimension	n (%)	n (%)	(1-7)
Self Care			
Swallowing	0 (0)	76 (97)	6-7
Feeding	0 (0)	67 (86)	5-7
Grooming	0 (0)	56 (72)	2-7
Bathing	0 (0)	62 (80)	2-7
Dressing (upper)	0 (0)	51 (65)	2-7
Dressing (lower)	0 (0)	51 (65)	2-7
Toileting	1 (1)	64 (82)	1-7
Bladder	1 (1)	74 (95)	1-7
Bowel Care	0 (0)	77 (99)	6-7
Mobility			
Bed Transfers	0 (0)	60 (77)	4-7
Toilet Transfers	0 (0)	59 (76)	4-7
Bath Transfers	0 (0)	51 (65)	3-7
Car Transfers	0 (0)	59 (76)	3-7
Locomotion	1 (1)	38 (49)	1-7
Stairs	5 (6)	34 (44)	1-7
Community Mobility	1 (1)	25 (32)	1-7

Table 5.15 Distributional characteristics of Cognitive FIM+FAM items (n=78)

Dimension	Floor n (%)	Ceiling n (%)	Range (1-7)
Communication			
Comprehension	0 (0)	34 (44)	2-7
Expression	0 (0)	33 (42)	3-7
Reading	0 (0)	18 (23)	3-7
Writing	0 (0)	36 (46)	2-7
Speech Intelligibility	0 (0)	49 (63)	3-7
Cognition			
Problem Solving	1 (1)	23 (30)	1-7
Memory	1 (1)	18 (23)	1-7
Orientation	1 (1)	30 (39)	1-7
Attention	1 (1)	20 (26)	1-7
Safety Judgement	1 (1)	26 (33)	1-7
Psychosocial			
Social Interaction	0 (0)	29 (37)	3-7
Emotion	0 (0)	15 (19)	2-7
Adjustment to Limits	1 (1)	28 (36)	1-7
Employability	1 (1)	10 (13)	1-7

Edinburgh Rehabilitation Status Scale

The Edinburgh Rehabilitation Status Scale (ERSS) which measures medicosocial dysfunction was completed for all 78 patients. A higher score indicates a lower level of functioning.

Edinburgh Rehabilitation Status Scale scores

Table 5.16 illustrates the total and four subscales scores. The highest mean score was obtained for the scale measuring the effect of symptoms on the individual's lifestyle.

Table 5.16 ERSS subscales and total scores (n=78)

ERSS subscale	Mean (SD)	Median
Support	1.9 (1.9)	1.0
Inactivity	2.8 (1.8)	3.0
Isolation	2.6 (1.7)	3.0
Effect of Symptoms	3.2 (1.6)	3.0
Total Score	10.4 (6.3)	9.5

Mean Edinburgh Rehabilitation Status Scale scores by age group

Table 5.17 shows that the two age groups have very similar scores for three of the four ERSS subscales and total score, with no significant differences being found between the groups.

Table 5.17 Mean ERSS scores by age group

ERSS subscale	16-35 yr olds (n=57)	50-65 yr olds (n=21)	p value (sig level†)
Support	1.6	2.5	0.090 (NS)
Inactivity	2.8	2.8	0.895 (NS)
Isolation	2.5	2.8	0.441 (NS)
Effect of Symptoms	3.1	3.3	0.528 (NS)
Total Score	10.1	11.4	0.423 (NS)

† NS=non-significant

Mean Edinburgh Rehabilitation Status Scale scores by severity of Traumatic Brain Injury

Figure 5.2 presents the mean ERSS scores by severity of injury. It illustrates that the moderate TBI sample tend to have lower scores (i.e. better functioning) than either the mild or severe groups. However, performing a Kruskal Wallis test revealed that no significant differences at $p<0.01$ level were found (Table 5.18). As noted previously, age may be a confounding factor and therefore a Kendall partial correlation controlling for age was performed for the ERSS total score. This found a very weak correlation between the ERSS score and severity (T_{xy} = -0.149) which was only slightly strengthened when age was controlled for ($T_{xy.z}$ = -0.175).

Figure 5.2 Mean ERSS scores by severity of TBI (n=78)

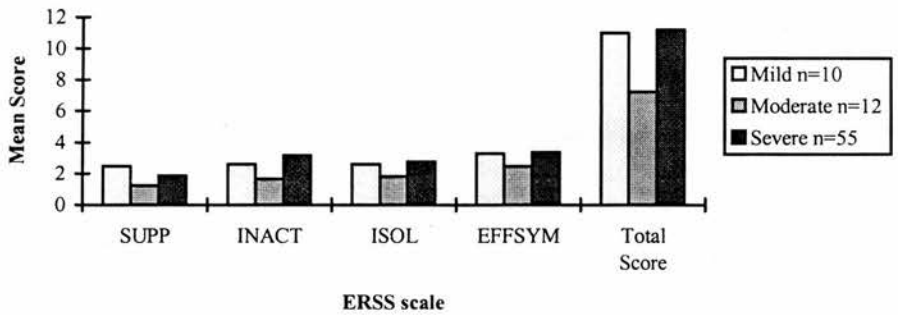


Table 5.18 Difference in ERSS scores by severity of TBI (n=78)

ERSS subscale	H	p value	significance level†
Support	1.85	0.397	NS
Inactivity	7.56	0.023	*
Isolation	3.41	0.182	NS
Effect of Symptoms	3.45	0.174	NS
Total Score	4.21	0.122	NS

† NS=non-significant, *=p<0.05

Mean Edinburgh Rehabilitation Status Scale scores by time post-injury

No significant differences were found relating to time post-injury.

Total Edinburgh Rehabilitation Status Scale score

The total ERSS score can be used to categorise patients into three functional levels. Scores of 0-8, 9-16 and 17-28 indicate high, moderate and low levels of functioning respectively. In this sample the majority of patients had either moderate or high levels of functioning (Table 5.19). Dividing the population by age, it is noted that almost a quarter of the older population are described as having a low level of functioning compared with 14% of the young population. The originators of the ERSS suggest that a patient with a score above 12 would find it very difficult to maintain any form of employment (even sheltered employment) (Affleck and McGuire, 1993). This would account for one third of this sample (26 patients) over 60% of whom belong to the younger age group.

Table 5.19 ERSS functional level by age group

	16-35 yr olds (n=57)	**50-65 yr olds (n=21)**	**Total (n=78)**
Functional level	n (%)	n (%)	n (%)
High (0-8)	23 (40)	8 (38)	31 (40)
Moderate (9-16)	26 (46)	8 (38)	34 (44)
Low (17-28)	8 (14)	5 (24)	13 (17)

Distributional characteristics of the Edinburgh Rehabilitation Status Scale

The distributional characteristics of the ERSS are shown in Table 5.20 and reveal that there were notable ceiling effects (>15%) for the Support and Isolation subscales but floor effects were not evident.

Table 5.20 Distributional characteristics of ERSS (n=78)

	Floor	**Ceiling**	**Range**
ERSS subscale	n (%)	n (%)	
Support	2 (3)	26 (33)	0-7
Inactivity	3 (4)	10 (13)	0-7
Isolation	0 (0)	13 (17)	0-6
Effects of Symptoms	0 (0)	5 (6)	0-6
Total Score	0 (0)	5 (6)	0-25

5.3.2 SELF REPORT MEASURES

Short Form 36

The Short Form 36 (SF-36) was administered with assistance being given by the author where required to aid understanding and method of completion. Seventy-two patients were able to attempt the SF-36 although almost half required some assistance (Table 5.21). Of the six patients who were not able to complete the questionnaire, four had sustained very severe injuries which had led to difficulties in understanding and communicating, and two had co-existing problems of Alzheimer's dementia or Down's Syndrome.

Table 5.21 Assistance required to attempt SF-36

Degree of help required	n (%)
No help	38 (49)
Occasional help	18 (23)
Continual help	13 (17)
Help due to visual difficulties only	3 (4)
Unable to complete	6 (8)
Total	78 (101)

Completeness of Short Form 36 data

The SF-36 was scored according to the guidelines produced by the Medical Outcomes Trust (Ware et al. 1993). As directed by this manual, items were re-coded, raw scale scores were computed by summing across items in the same scale and then transformed to produce a scale score between 0-100. Because of the multi-item nature of the SF-36 it is possible, in certain circumstances, to estimate the scale score even though responses to some items are missing. Table 5.22 details the percentage of patients who returned fully completed scales, and following the specified procedure for missing data, the percentage who had computable scales. Of those who were able to attempt the SF-36, at least 99% had computable scales, although many patients had required assistance.

Table 5.22 Complete and computable SF-36 scales (n=72)

SF-36 scale	Complete scales n (%)	Computable scales n (%)
Physical Functioning (PF)	70 (97)	71 (99)
Physical Role Limitations (RP)	72 (100)	72 (100)
Bodily Pain (BP)	72 (100)	72 (100)
General Health Perceptions (GH)	69 (96)	71 (99)
Vitality (VT)	70 (98)	71 (99)
Social Functioning (SF)	71 (99)	72 (100)
Emotional Role Limitations (RE)	72 (100)	72 (100)
General Mental Health (MH)	70 (97)	71 (99)

Short Form 36 scale scores

The mean and median scores for the eight scales of the SF-36 are detailed in Table 5.23. A higher score indicates better perceived health status. The highest score was for Bodily Pain and the lowest scores for Physical Role Limitations, General Health, Emotional Role Limitations and Vitality. The full range of score distribution was observed for each of the eight scales.

Table 5.23 SF-36 scale scores

SF-36 scale	n	Mean (SD)	Median	Range (%)
Physical Functioning	71	64.5 (29.8)	70.0	0-100
Physical Role Limitation	72	54.2 (42.2)	62.5	0-100
Bodily Pain	72	75.4 (28.7)	84.0	0-100
General Health Perceptions	71	56.6 (27.0)	60.0	0-100
Vitality	71	57.7 (24.6)	60.0	0-100
Social Functioning	72	66.7 (30.0)	75.0	0-100
Emotional Role Limitation	72	57.4 (45.2)	66.7	0-100
General Mental Health	71	65.0 (23.7)	68.0	0-100

Mean Short Form 36 scale scores by age group

Figure 5.3 illustrates the mean scores for each of the eight scales for the older and younger age groups (the abbreviations used in the figure are detailed in Table 5.22). The lowest scores were found for Emotional Role Limitations in the younger age group and Physical Functioning in the older group. No significant differences were found between the age groups at the $p<0.01$ or $p<0.001$ level (Table 5.24).

Figure 5.3 Mean SF-36 scale scores by age group (n=72)

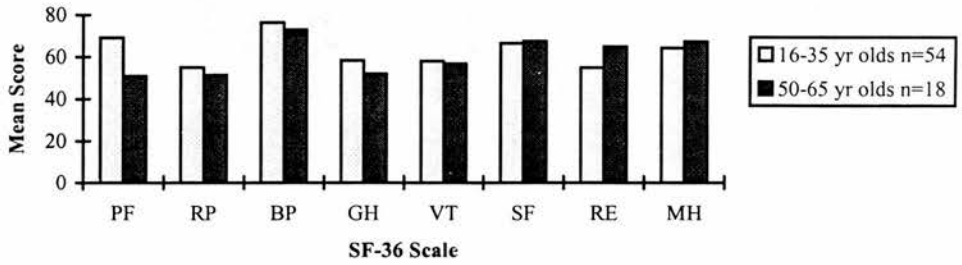


Table 5.24 Difference in SF-36 scale scores by age group

SF-36 scale	U	p value	significance level†
Physical Functioning	327.50	0.047	*
Physical Role Limitation	470.50	0.834	NS
Bodily Pain	479.00	0.924	NS
General Health Perceptions	421.00	0.459	NS
Vitality	438.00	0.776	NS
Social Functioning	467.50	0.806	NS
Emotional Role Limitation	415.00	0.318	NS
General Mental Health	399.50	0.422	NS

† NS=non-significant, *=$p<0.05$

Mean Short Form 36 scale scores by severity of Traumatic Brain Injury

The mean SF-36 scale scores for each of the severity groups are illustrated in Figure 5.4. No obvious pattern was apparent between the three groups and a Kruskal Wallis test revealed that there were no significant differences (Table 5.25).

Figure 5.4 Mean SF-36 scale scores by severity of TBI (n=72)

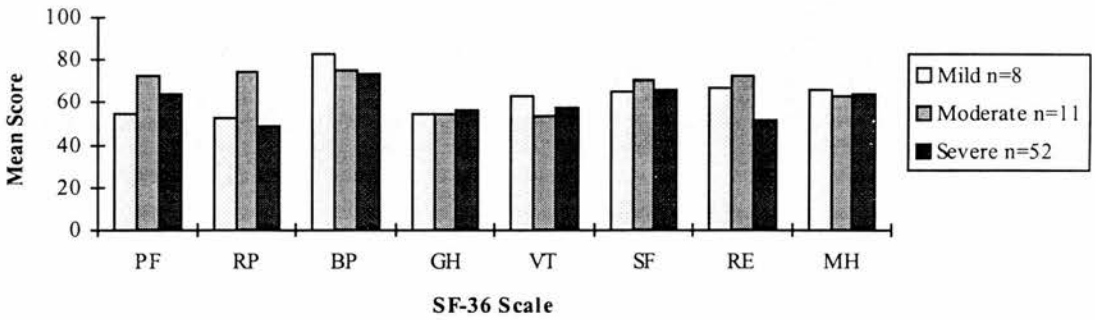


Table 5.25 Difference in SF-36 scale scores by severity of TBI

SF-36 scale	H	p value	significance level†
Physical Functioning	2.15	0.340	NS
Physical Role Limitation	3.84	0.146	NS
Bodily Pain	1.77	0.412	NS
General Health Perceptions	0.079	0.961	NS
Vitality	1.45	0.483	NS
Social Functioning	0.165	0.921	NS
Emotional Role Limitation	2.67	0.263	NS
General Mental Health	0.414	0.813	NS

† NS=non-significant

In order to determine the effect of age on the results, Kendall partial correlations controlling for age were undertaken. However this revealed that there was no association between severity of TBI and the SF-36 scores, even when age was controlled for (Table 5.26).

Table 5.26 Kendall partial correlations between SF-36 score and severity of TBI (by GCS score) controlling for age at injury

SF-36	Correlation between SF-36 score and severity (T_{xy})	Partial correlation controlling for age ($T_{xy.z}$)
Physical Functioning	0.027	0.074
Physical Role Limitation	0.068	0.087
Bodily Pain	0.104	0.093
General Health Perceptions	-0.017	-0.016
Vitality	0.054	0.036
Social Functioning	0.036	0.051
Emotional Role Limitation	0.125	0.097
General Mental Health	0.093	0.079

Mean Short Form 36 scale scores by time post-injury

No significant differences were found between the length of time post-injury and the SF-36 scores.

Distributional characteristics of Short Form 36 scales

Noteworthy floor effects were observed for the Physical and Emotional Role Limitations scales (32% and 33% respectively) (Table 5.27). These two scales also had substantial ceiling effects (35% and 47%) as did Bodily Pain (44%) and Social Functioning (31%).

Table 5.27 Distributional characteristics of SF-36 scales

		Floor	Ceiling
SF-36 scale	**n**	n (%)	n (%)
Physical Functioning	71	5 (7)	4 (6)
Physical Role Limitation	72	23 (32)	25 (35)
Bodily Pain	72	2 (3)	32 (44)
General Health Perceptions	71	2 (3)	2 (3)
Vitality	71	4 (6)	4 (6)
Social Functioning	72	3 (4)	22 (31)
Emotional Role Limitation	72	24 (33)	30 (47)
General Mental Health	71	1 (1)	3 (4)

Functional Limitations Profile

The Functional Limitations Profile (FLP) was completed by interview with 74 of the 78 patients (95%), some of whom required assistance. The four patients who were unable to co-operate had severe communication and cognitive problems. Statements were read to the patient who indicated whether they agreed or disagreed and whether or not this was due to their health. Higher scores on the FLP indicate greater sickness related dysfunction.

Functional Limitations Profile scores

Table 5.28 shows that greatest dysfunction was found for Work, Alertness, Recreation and Sleep and Rest, the latter three of these categories belonging to the Psychosocial dimension.

Table 5.28 FLP scores (n=74)

FLP subscale	Mean % (SD)	Median %
Overall Score	15.0 (11.1)	12.6
Physical Dimension	9.5 (12.7)	5.5
Psychosocial Dimension	20.2 (14.7)	16.7
Physical		
Ambulation (AM)	14.7 (17.6)	10.1
Body Care (BC)	6.6 (10.7)	3.4
Mobility (MB)	4.8 (10.2)	0.0
Household Management (HM)	14.8 (23.9)	2.7
Psychosocial		
Social Interaction (SI)	13.5 (14.0)	10.0
Emotion (EM)	14.0 (19.3)	0.0
Alertness (AL)	35.4 (30.1)	29.8
Sleep & Rest (S&R)	17.0 (15.5)	14.6
Recreation (RC)	30.6 (25.2)	32.0
Others		
Communication (CM)	12.7 (16.2)	7.3
Eating (EAT)	0.8 (2.2)	0.0
Work (WK)	46.5 (31.2)	69.4

Mean Functional Limitations Profile scores by age group

The mean FLP scores for the two age groups are illustrated in Figures 5.5 and 5.6 (the abbreviations used are detailed in Table 5.28). On initial inspection, the younger population appear to have lower scores than the older population for the majority of scales, indicating better health. However, only Work and Mobility were found to have statistically significant differences between the age groups (Table 5.29). The overall FLP and dimension scores did not show statistically significant differences between the age groups.

Figure 5.5 Mean FLP scores by age group (n=74)

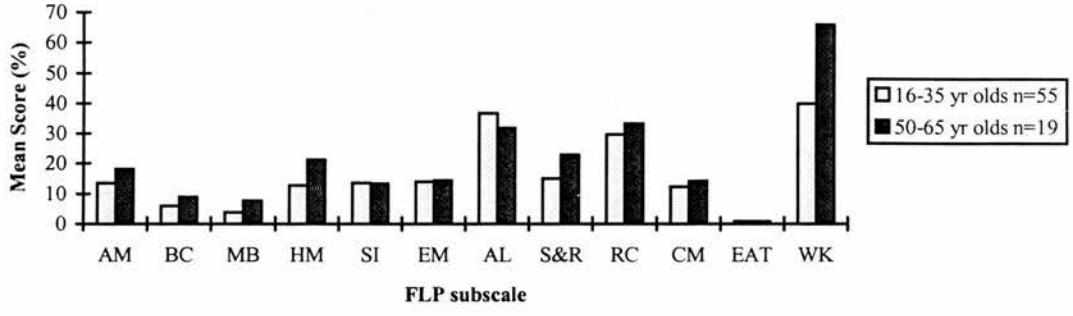


Figure 5.6 Mean FLP dimension and total scores by age group (n=74)

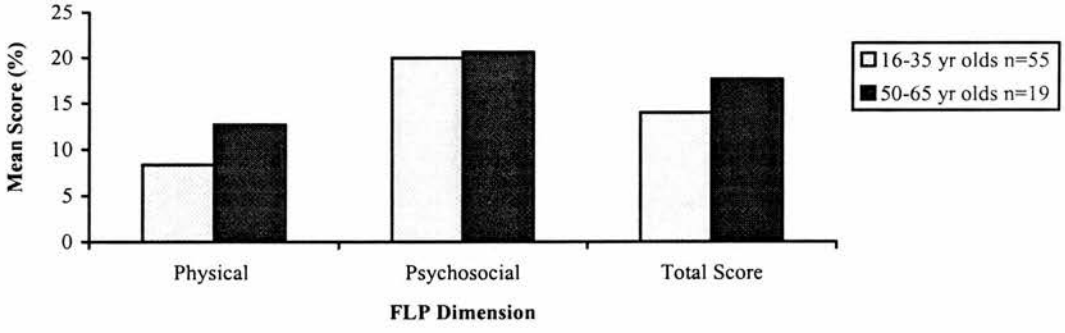


Table 5.29 Difference in FLP scores by age, severity of TBI and time post-injury (n=74)

FLP subscale	Age groups p (sig level†)	Severity of TBI p (sig level†)	Time post-injury p (sig level†)
Overall Score	0.194 (NS)	0.591 (NS)	0.352 (NS)
Physical Dimension	0.208 (NS)	0.356 (NS)	0.480 (NS)
Psychosocial Dimension	0.926 (NS)	0.814 (NS)	0.292 (NS)
Physical			
Ambulation	0.106 (NS)	0.310 (NS)	0.431 (NS)
Body Care	0.995 (NS)	0.204 (NS)	0.417 (NS)
Mobility	0.009 (**)	0.065 (NS)	0.309 (NS)
Household Management	0.211 (NS)	0.450 (NS)	0.303 (NS)
Psychosocial			
Social Interaction	0.985 (NS)	0.643 (NS)	0.839 (NS)
Emotion	0.958 (NS)	0.836 (NS)	0.690 (NS)
Alertness	0.404 (NS)	0.720 (NS)	0.481 (NS)
Sleep & Rest	0.085 (NS)	0.246 (NS)	0.374 (NS)
Recreation	0.532 (NS)	0.676 (NS)	0.257 (NS)
Others			
Communication	0.245 (NS)	0.341 (NS)	0.855 (NS)
Eating	0.827 (NS)	0.864 (NS)	0.550 (NS)
Work	0.002 (**)	0.204 (NS)	0.895 (NS)

† NS=non-significant, **=p<0.01

Mean Functional Limitations Profile scores by severity of Traumatic Brain Injury

Figures 5.7 and 5.8 illustrate the mean FLP scores by severity of TBI. They show that all three severity groups reported relatively similar levels of sickness related dysfunction which does not appear to be related to injury severity. This was confirmed by performing a Kruskal Wallis test which indicated that there was no significant difference between the three groups (Table 5.29).

Figure 5.7 Mean FLP scores by severity of injury (n=73)

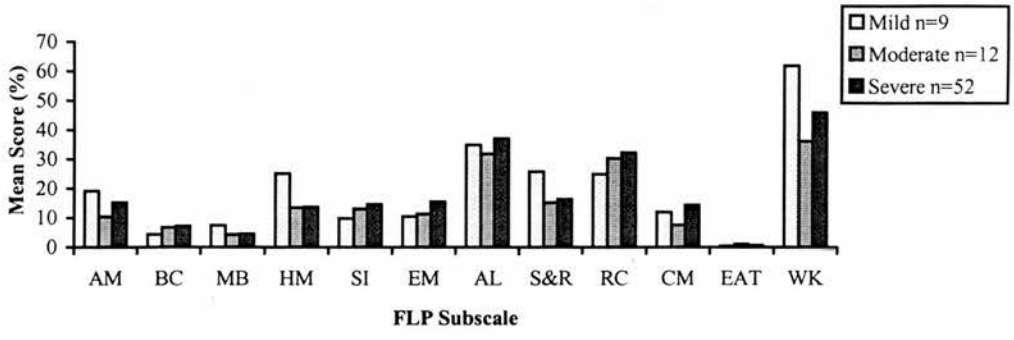
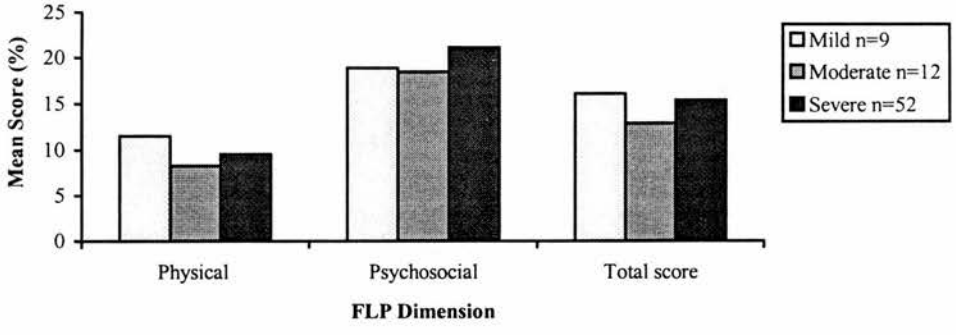


Figure 5.8 FLP dimensions and total score by severity of TBI (n=73)



In order to control for the effects of age, Kendall partial correlations were undertaken (Table 5.30). Results revealed that there was no association between severity of TBI and FLP score, even when age was controlled for.

Table 5.30 Kendall partial correlations between FLP summary scores and severity of TBI (by GCS score) controlling for age at injury

FLP	Correlation between FLP score and severity (T_{xy})	Partial correlation controlling for age ($T_{xy \cdot z}$)
Total Score	-0.051	-0.085
Physical Dimension	-0.049	-0.090
Psychological Dimension	-0.025	-0.031

Mean Functional Limitations Profile scores by time post-injury

No significant differences were found relating to time post-injury (Table 5.29).

Distributional characteristics of Functional Limitations Profile

Although there were no floor effects, noteworthy ceiling effects were evident across each of the FLP subscales and the Physical dimension summary score (Table 5.31). This indicates that whilst the FLP may not be able to identify those with minor difficulties, it adequately describes those with severe problems.

Table 5.31 Distributional characteristics of FLP (n=74)

	Floor	Ceiling	Range
FLP subscale	n (%)	n (%)	(0-100%)
Overall Score	0 (0)	3 (4)	0-49
Physical Dimension	0 (0)	18 (24)	0-69
Psychosocial Dimension	0 (0)	5 (7)	0-55
Physical			
Ambulation	1 (1)	25 (34)	0-100
Body Care	0 (0)	35 (47)	0-50
Mobility	0 (0)	54 (73)	0-49
Household Management	2 (3)	37 (50)	0-100
Psychosocial			
Social Interaction	0 (0)	17 (23)	0-54
Emotion	0 (0)	38 (51)	0-65
Alertness	2 (3)	17 (23)	0-100
Sleep & Rest	0 (0)	23 (31)	0-51
Recreation	0 (0)	19 (26)	0-94
Others			
Communication	0 (0)	33 (45)	0-64
Eating	0 (0)	65 (88)	0-10
Work	0 (0)	14 (19)	0-69

Community Integration Questionnaire

As previously mentioned the CIQ was introduced at the midway point in the study and therefore was only completed by half the study population. A low score on the CIQ indicates poorer integration.

Community Integration Questionnaire scores

Table 5.32 illustrates the CIQ subscale and total scores and shows that the lowest score was for Productivity. Because of the small numbers in each group, the CIQ data has not been analysed to determine differences between groups in terms of age, severity of injury or time post-injury.

Table 5.32 CIQ scores (n=39)

CIQ subscale	Mean (SD)	Median
Home Integration	5.9 (4.0)	5.0
Social Integration	8.5 (2.6)	9.0
Productivity	3.4 (1.9)	2.0
Overall Score	17.7 (5.9)	18.0

Distributional characteristics of Community Integration Questionnaire

Table 5.33 illustrates the distributional characteristics of the CIQ in this population. It reveals that only Home Integration has ceiling effects with just under half the population obtaining the maximum score.

Table 5.33 Distributional characteristics of CIQ (n=39)

	Floor	Ceiling	Range
CIQ subscale	n (%)	n (%)	
Home Integration	5 (13)	17 (44)	0-10
Social Integration	0 (0)	0 (0)	3-12
Productivity	0 (0)	0 (0)	1-6
Overall Score	0 (0)	0 (0)	4-28

5.3.3 RELATIVE/CARER COMPLETED SCALES

Short Form 36

The SF-36 (with minor alterations to the wording) was given to a relative or close friend who was asked to complete the questionnaire based on their opinion of the patient. Fifty seven of the 78 relatives (73%) returned the SF-36.

Completeness of Short Form 36 data

Table 5.34 details the percentage of complete and computable SF-36 scales returned by relatives. The two Role Limitation scales have the lowest percentage of computable scores reflecting difficulties experienced by the relative in assessing the current status of the patient.

Table 5.34 Complete and computable SF-36 scales by relatives (n=57)

	Complete scales	Computable scales
SF-36 scale	n (%)	n (%)
Physical Functioning (PF)	52 (91)	56 (98)
Physical Role Limitations (RP)	51 (90)	53 (93)
Bodily Pain (BP)	54 (95)	56 (98)
General Health Perceptions (GH)	54 (95)	56 (98)
Vitality (VT)	54 (95)	56 (98)
Social Functioning (SF)	54 (95)	56 (98)
Emotional Role Limitations (RE)	51 (90)	51 (90)
General Mental Health (MH)	53 (93)	56 (98)

Comparison of patient and relative Short Form 36 scores

The mean SF-36 scale scores provided by the patient and relative appear similar and there was no consistent pattern with one party scoring higher or lower than the other (Figure 5.9). Comparing the grouped data revealed that only Physical Functioning, Emotional Role Limitations and Mental Health have correlation coefficients above 0.5 (Table 5.35). Although some of the other scales are found to reach significance level the correlations are low.

Figure 5.9 Mean patient and relative SF-36 scale scores

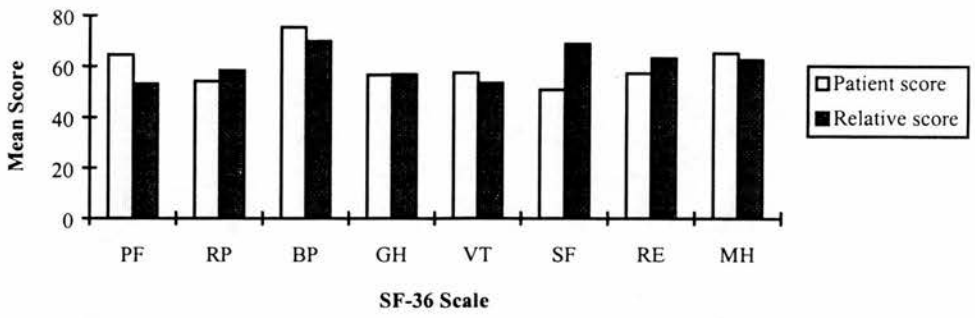


Table 5.35 Spearman's rank correlations between patient and relative completed SF-36 scales

SF-36 scale	n	r_s	p value	significance level†
Physical Functioning	50	+0.51	<0.001	***
Physical Role Limitation	48	+0.39	0.007	**
Bodily Pain	51	+0.45	0.001	**
General Health Perceptions	51	+0.39	0.005	**
Vitality	50	+0.29	0.043	*
Social Functioning	51	+0.45	0.001	**
Emotional Role Limitation	46	+0.50	<0.001	***
General Mental Health	50	+0.53	<0.001	***

† *=p<0.05, **=p<0.01, ***=p<0.001

Katz Adjustment Scale - Relatives Questionnaire

The Katz Adjustment Scale (KAS-R1) was completed by 48 relatives providing pre and post-injury ratings for the patient. The ten subscale scores, as described by Goran and Fabiano (1993) are presented in Table 5.36. Highest post-injury scores, indicating poorest neurobehavioural status, are found for Social Irresponsibility, Emotional Sensitivity and Belligerence.

Table 5.36 Pre and post-injury KAS-R1 scores (n=48)

	Pre-injury		Post-injury	
KAS-R1	Mean (SD)	Median	Mean (SD)	Median
Belligerence	14.8 (4.7)	14.0	18.6 (7.1)	17.0
Apathy	5.13 (2.1)	4.0	8.2 (2.9)	8.0
Social Irresponsibility	16.0 (6.0)	15.0	19.6 (4.9)	19.0
Orientation	6.8 (2.7)	5.0	9.1 (3.7)	8.0
Antisocial Behaviour	9.0 (2.8)	8.0	10.1 (3.8)	8.0
Speech/Cognitive Dysfunction	11.5 (4.2)	10.0	16.5 (5.7)	15.5
Bizarreness	10.3 (2.3)	9.0	12.3 (3.6)	11.0
Paranoid Ideation	11.6 (3.2)	10.0	15.0 (6.0)	12.0
Verbal Expansiveness	11.1 (1.9)	10.0	10.8 (2.5)	10.0
Emotional Sensitivity	13.3 (5.1)	11.0	19.6 (6.8)	19.0

Wilcoxon signed rank tests revealed that there were highly significant differences between the pre and post-injury scores for the majority of subscales, with poorer behaviour being reported after the injury (Table 5.37). However because of the problems of retrospective assessment by the relative, these findings are difficult to interpret. No differences were found in post-injury scores between the age or severity groups or relating to time post-injury.

Table 5.37 Difference between pre and post-injury KAS-R1 scores

KAS-R1	Z	p value	significance level†
Belligerence	-4.024	<0.001	***
Apathy	-5.331	<0.001	***
Social Irresponsibility	-3.899	<0.001	***
Orientation	-4.089	<0.001	***
Antisocial Behaviour	-2.116	0.034	*
Speech/Cognitive Dysfunction	-4.978	<0.001	***
Bizarreness	-3.636	<0.001	***
Paranoid Ideation	-4.446	<0.001	***
Verbal Expansiveness	-1.143	0.253	NS
Emotional Sensitivity	-5.045	<0.001	***

† NS=non-significant, *=p<0.05, ***=p<0.001

5.3.4 Outcome measures by Glasgow Outcome Scale category

A Kruskal Wallis test was used to compare the mean SF-36, FLP, ERSS, CIQ and FIM+FAM scores across the three GOS categories (Table 5.38). For the SF-36, only the Physical Functioning scale shows a significant difference between the GOS categories, with the severely disabled reporting poorest health. The lack of significant results for the remaining SF-36 scales might indicate that the SF-36 does not reflect level of dependence in the same way as the GOS. Significant differences were found between the three GOS categories for the FLP Physical dimension and total score but not for the Psychological dimension. This might be because it is physical rather than psychological deficits which have led to dependence in this sample. Both the Motor and Cognitive FIM+FAM scores show highly significant differences on the GOS and this would be expected as both measures are concerned with dependence levels. The ERSS total score also shows highly significant results, but the CIQ does not and this may reflect the small sample size for this measure.

Table 5.38 SF-36, FLP, ERSS, CIQ and FIM+FAM mean scores by GOS category

	Good Recovery	Moderate Disability	Severe Disability	p value (sig level†)
SF-36				
Physical Functioning	74.1	60.8	27.9	0.001 (**)
Physical Role Limitation	65.8	43.0	39.3	0.099 (NS)
Bodily Pain	79.6	72.4	68.0	0.815 (NS)
General Health Perceptions	64.2	50.7	36.9	0.024 (*)
Vitality	66.1	51.0	40.0	0.010 (*)
Social Functioning	74.3	60.5	51.8	0.141 (NS)
Emotional Role Limitation	69.3	42.7	52.4	0.119 (NS)
General Mental Health	69.7	61.6	58.3	0.214 (NS)
FLP				
Physical Dimension	3.8	12.1	29.2	<0.001 (***)
Psychological Dimension	16.3	24.9	24.2	0.031 (*)
Total Score	10.1	18.6	27.6	<0.001 (***)
ERSS Total Score	6.3	12.8	19.4	<0.001 (***)
CIQ Total Score	19.6	16.8	10.3	0.014 (*)
FIM+FAM				
Motor	103.3	99.9	84.6	<0.001 (***)
Cognitive	94.3	82.4	64.7	<0.001 (***)

† NS=non-significant, *=p<0.05, **=p<0.01, ***=p<0.001

5.4 DISCUSSION

DESCRIPTIVE DATA

Sample and response rate

The sample for this study was drawn from TBI admissions to the AAH over a seven year period. Patients were aged either 16-35 years or 50-65 years at the time of the injury and were resident in either Lothian or Fife. Seventy-eight of the 110 eligible patients completed the interview (71%) which is a good response rate in a mobile population who are notoriously difficult to follow up (Brooks and Aughton, 1979). Patients who participated in the study were found to be similar in terms of age and severity of injury as those who refused.

Demographic and injury data

The majority of the descriptive and injury data was obtained from the acute neurosurgical unit database and from clinical notes. In most cases it was possible to check the GCS scores from the clinical notes, but unfortunately the duration of PTA was only available for a few patients and therefore this data has not been reported. In this sample, 71% were severely injured, 15% were moderately injured and 13% mildly injured. The younger population were significantly more likely to have sustained a severe TBI. Whilst clearly this sample is not representative of the TBI population as a whole, it does reflect the nature of patients admitted to a brain injury rehabilitation unit (Gray et al. 1994; Ponsford et al. 1995). The male to female ratio found in this study was also similar to that reported in other studies (Rappaport et al. 1989; Gray et al. 1994; Jennett, 1996).

The cause of injury was shown to vary with age and injury severity. In the younger population, 65% were due to RTAs whereas in the older population 62% were due to falls, a pattern which is commonly reported (Kraus et al. 1984; Gray et al. 1994; Jennett, 1996). The cause of injury also influences the type of intracranial lesions sustained. Diffuse axonal injury was found to be more common in the younger population which relates to the acceleration/deceleration injuries typical of an RTA (Adams et al. 1982; Gennarelli et al. 1982b; Adams et al. 1989). The falls sustained by the older population tend to cause skull fractures and intracranial haematomas.

Outcome measures and data collection

Data was collected by means of a semi-structured interview involving a number of outcome measures, some of which had been previously used with the TBI population. Several different sources of information were available including the patient, relative and interviewer. Although there is debate over the use of self report measures in a TBI population, it was felt to be appropriate in this study because of the length of time post-injury and the subjective nature of many of the questions. It is known that as time post-injury increases, social, emotional and behavioural issues tend to predominate over physical problems (Thomsen, 1984; Brooks et al. 1987). Therefore obtaining the patient's view of these areas, in combination with assessment by the relative and interviewer is important, and thought to be crucial by some researchers (Tyerman and Humphrey, 1984).

Missing data

Because information was collected primarily by means of face-to-face interview, there is a very low rate of missing data from the patient population. However some data was also required from relatives and this was only possible in around three-quarters of cases. Missing data generated from the SF-36 was dealt with in the manner suggested by the originators which involves substituting average scores for that subscale (Ware et al. 1993). Any missing data for the other scales was coded as such.

Interviewer completed measures

Glasgow Outcome Scale

The author rated the global outcome on the GOS, which although known to be a fairly crude measure, is widely used to describe TBI outcome. In this study, 51% had made a good recovery, 35% had moderate disability and 14% had severe disability (see Table 5.8). However, there were no significant differences in GOS score between the age, severity and time post-injury groups.

Masson et al. (1996) undertook a community based study in France in a mixed severity population (65% mild, 20% moderate, 15% severe). At five years post-injury a good recovery on the GOS was documented for 97% of the mild, 94% of the moderate and 41% of the severe TBIs. The equivalent figures in the current study are 60%, 75% and 44% respectively. The difference in outcome for the mild and moderate patients may relate to differences in classification of severity. For example in the French study, an 'abnormal CT scan' would classify a patient as a moderate TBI, whereas the current study relied primarily

on the GCS score. This emphasises the importance of using widely accepted criteria to allow comparison between patient samples.

Jennett et al. (1981) reported on disability six months after severe head injury using the GOS, and found that 40% had a good recovery, 40% had moderate disability and 20% had severe disability. Although the current study took place much longer after injury, the results from the severely injured sample are very similar. This may be because the majority of recovery takes place in the first six to twelve months, and that little change in category occurs subsequently (Jennett and Bond, 1975; Teasdale and Jennett, 1976; Jennett et al. 1977; Diller and Ben Yishay, 1987). However, given the scope of the GOS categories, each will include individuals with quite a wide range of abilities and progress between categories would require considerable improvement. The lack of improvement found in studies may largely be due to the insensitivity of the GOS (Wade, 1992b; Clifton et al. 1993) and a more detailed measure might be able to detect lesser degrees of change. In addition, although improvements may seem small to the clinician, they may serve to enhance the independence level and quality of life for the patient and his family (Guyatt et al. 1998).

Clearly the choice of scale must be guided by the purpose of the assessment. Although the GOS is not ideal, it was included in this study as a recommended measure of global outcome following TBI which allows comparison with previous research (Clifton et al. 1992). The lack of significant results for the GOS score may suggest that in the long term, outcome from TBI is not directly related to the initial severity of TBI or age of the patient (Corrigan et al. 1998). It may be that the GOS is not suitable for use many years after injury as it was designed to assess only the effects of the TBI and not to take into account other unrelated problems. This is however awkward in the longer term when it may be difficult to determine which problems were due to the original injury.

Functional Assessment Measure

The FIM+FAM revealed that the current patient sample were independent in 28 of the 30 areas assessed and no significant differences were found between the age, severity and time post-injury groups. Comparable summary score results have been found in other long term research, for example Hall et al. (1996) who studied a group of mixed severity TBI patients at two years post-injury. Corrigan et al. (1998) reported only FIM scores in their study up to five years post-injury, and found that the mean FIM Motor score was 85 and the mean FIM

Cognitive score was 32. These are very similar to the figures found in this study (86 and 29 respectively).

The FIM+FAM is known to be useful for clinical and research purposes in the early stages after injury (Hall, 1992; Pentland and McPherson, 1994). However this study would suggest that it is of limited use in assessing functional ability in the long term because of the very large ceiling effects found across all items. Hall et al. (1996) also found ceiling effects in a third of cases when the FIM+FAM was used at one and two years post-injury and concluded that the measure was not sensitive to change at this time. It would therefore appear that the FIM+FAM cannot adequately assess key cognitive, behavioural and psychosocial issues at the community level.

Edinburgh Rehabilitation Status Scale

No significant differences were found between the age, severity and time post-injury groups for the ERSS subscales. However, over a third of the sample were found to have a score above 12 which is thought to indicate that an individual would find it difficult to maintain any form of employment. This was confirmed for this sample by reviewing the employment status of the patients. The ERSS has been used previously in populations with mental and/or physical disabilities (Roy, 1991; Mattison et al. 1992; Disler et al. 1993) and was reported to be a sensitive index of overall function and to correlate well with hours of care required. It has also been included in the assessment of TBI patients (Gray et al. 1994; Anderson et al. 1996) and found to relate to negative symptoms in the first year after discharge (Gray et al. 1994). The present study found that the ERSS was quick and easy to complete and may make a useful contribution in determining the likelihood of maintaining employment. However, mean scores were found to be low compared with other research (Roy, 1991) and correspondingly ceiling effects were noted in two of the subscales which may limit its use. The validity of the ERSS is yet to be fully established.

Self report measures

Short Form 36

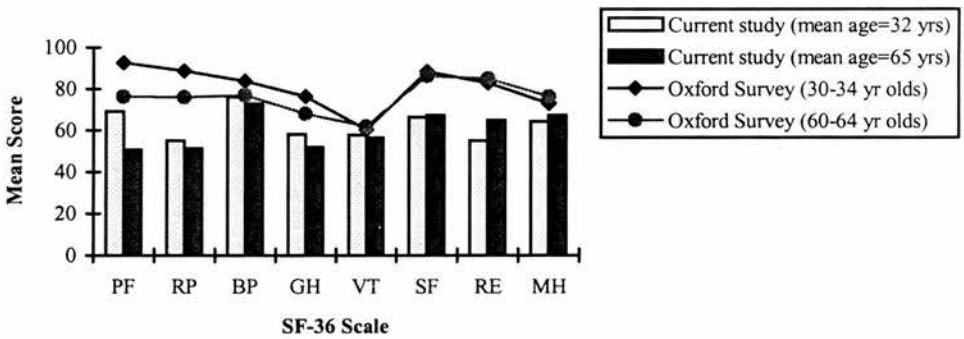
Over 90% of the patient sample were able to complete the SF-36 questionnaire by interview. The percentage of computable SF-36 subscales ranged from 99-100% although it must be emphasised that almost 50% had required assistance to complete the questionnaire hence reducing the degree of missing data. Poor self reported health was found across both physical and mental health subscales. However no significant differences (at the $p<0.01$

level) were found between the SF-36 scores and age group, severity of TBI or time post-injury. These results may relate to the small sample size in this study. However, Corrigan et al. (1998) also reported that SF-36 scores remained stable over the first five years after injury.

Normative and Traumatic Brain Injury Short Form 36 data

Figure 5.10 illustrates the normative data for the SF-36 from the Oxford Healthy Lifestyle Survey (1996) alongside the current study data to allow comparison. It is clear that for the majority of scales both TBI age groups reported poorer health than either group from the general population. The two Role Limitations scales, Physical Functioning and Social Functioning showed the biggest discrepancy between the TBI patients and norms. Corrigan et al. (1998) reported that the Physical and Mental component scores for a TBI population were poorer than that of the general population.

Figure 5.10 Normative and TBI data for SF-36 scales by age group



Note: Oxford survey provides normative data for the UK

When the distributional characteristics of the SF-36 were reviewed, floor effects were found for a third of the sample for the two Role Limitation scales indicating that further deterioration could not be detected. Similarly at the other end of the spectrum, four scales showed substantial ceiling effects and therefore any further improvement would not be shown on the SF-36. As might be predicted, lesser ceiling effects (except for Bodily Pain and Vitality) and greater floor effects are found for the TBI sample compared with the general population (McHorney et al. 1994a).

Functional Limitations Profile

The FLP was completed by 95% of the sample by means of an interview. Because of the style of the questionnaire, missing data was not generated as subjects only respond to items which relate to them. The results reveal that greatest dysfunction was evident in the Psychosocial rather than the Physical dimension, and this would be consistent with other research (Thomsen, 1984; Brooks et al. 1987). Significant differences were found between the age groups for Work and Mobility and this might be expected as many in the older group had reached retiral age and mobility tends to reduce with age. No differences were found with regard to severity of injury. Large ceiling effects were evident across all FLP subscales indicating that further improvement would not be detected on the FLP. These ceiling effects, particularly in the Physical Dimension, limit the use of the FLP many years after TBI.

It is difficult to compare the current study's findings with other TBI research because the US version of the FLP (the SIP) has different weightings and methods of calculating summary scores. It is thought that a non-patient population would score only two or three on the SIP while those with a terminal illness might score over 30 (Bowling, 1997b). Hall (1987), studying patients attending their GP, found that SIP scores were skewed towards the healthy end with no patients scoring above 25. In the current study, the mean total FLP score was 15 (range 0-49).

As with any self report measure it is possible that respondents may miss out questions or deny problems. Because of the method of completion of the SIP/FLP, where respondents only tick the box if the item relates to them, this measure may be particularly prone to this problem. This method does reduce the amount of time required to complete the questionnaire, but it is clearly more difficult to determine whether the respondent has read all items, compared to a measure such as the SF-36 where responses are required to every item.

Community Integration Questionnaire

The results of the CIQ from the present study are comparable to those reported by Corrigan et al. (1998) and Sander et al. (1997). Sander et al. (1997) also found that there was acceptable agreement between patient and family ratings. In the current study ceiling effects were evident in more than 40% of the sample for the Home Integration scale. Hall et al. (1996) also reported substantial ceiling effects for the Home and Social Integration scales in a mixed severity population up to two years post-injury. However, she defined the ceiling effect as the number of patients who reached the average value found for controls in previous research (Willer et al. 1994). However this, as noted by Dijkers (1997), is not the true ceiling, which is the maximum for/of the scale.

The CIQ is the most commonly used and best single measure of community integration in the TBI population (Hall and Johnston, 1994; Corrigan and Deming, 1995) and in the present study, it did appear to be an acceptable measure many years after injury. Although the CIQ does have adequate reliability and validity, the measure may not be sufficiently detailed to monitor community integration clinically (Dijkers, 1997). One of the drawbacks of the CIQ is that a patient will achieve a lower score (i.e. poorer integration) if he does not participate in an activity, even if this does not indicate a change from before the injury. This problem could be overcome by performing a retrospective pre-injury assessment of the patient (Hall and Johnston, 1994).

Relative/carer completed measures

Short Form 36

Almost three quarters of relatives completed an SF-36 questionnaire based on their view of the patient. When the grouped patient and relative scores were compared for each scale, it was shown that the scores were relatively similar, and there was no consistent pattern with one party scoring higher or lower than the other. Significant correlations between patient and relative were found for the Physical Functioning, Emotional Role Limitations and Mental Health scales only. It should be noted that this is not a recognised method of using the SF-36, and therefore firm conclusions cannot be drawn from the data. However, it is interesting to note that the patients reported poorer health than their relatives for Physical Functioning, Bodily Pain and Vitality, as it is often suggested that TBI patients tend to underestimate their difficulties. It may be however that patients tend to focus on physical rather than cognitive problems. These results should not be over-interpreted but they do

suggest that for some areas of health, information from the relative may be associated with how the patient feels.

Katz Adjustment Scale - Relatives Questionnaire

The KAS-R1 data does find a significant difference in pre and post-injury scores but because of concerns over the reliability of pre-injury assessments, the data was not further analysed. Informants found the questionnaire difficult to complete and some items unacceptable. The length of the questionnaire was also prohibitive. The KAS-R1 was therefore not felt to be suitable for this patient population many years after injury.

Difference in outcome between age groups, injury severity groups and time post-injury

It is interesting that no significant differences were found between the age groups, severity groups or relating to time post-injury on any of the interviewer completed or self report scales (apart from the FLP) as it is generally assumed that these factors affect outcome. To determine whether age was a confounding factor, partial correlations were performed, but even when age was controlled for only weak associations between the outcome measure and initial TBI severity were found.

One of the reasons for the lack of statistically significant findings in this study may relate to the sample size. Although the number of patients involved was comparable with many follow up studies of TBI patients (Thomsen, 1984; Thomsen, 1987; Corrigan et al. 1998), it may not have been large enough to detect differences in outcome. Another important factor may relate to the assignment of the initial severity of injury category based on GCS score. Although the GCS is a useful measure of initial severity, it may not relate to long term outcome. Unfortunately, it was not possible to retrospectively assess the duration of PTA in this study because of the time post-injury but this would have provided an additional indicator of severity. However, Corrigan et al. (1998) have reported that it was not possible to predict outcome based upon pre-morbid characteristics, severity of injury or early functional abilities.

It may be that over time, outcome in the different injury severity categories tend to converge. The majority of studies tend to concentrate on the severely injured population rather than looking across the severity spectrum. Hellawell (1998), studying moderate and severely injured patients, found that the moderate TBI patients had ongoing cognitive

deficits affecting their daily life which were similar to those who had sustained severe injuries. One study which has looked at all severities of injury (Masson et al. 1996) reported that subjective complaints and behavioural problems were prevalent across all severity groups. They suggest that patients may attribute all their symptoms to their TBI, or that accompanying social or medical events may have worsened the problems. From their study, Masson et al. (1996) have proposed that even mildly injured patients should be followed up and have psychological assessment. However, given the number of patients who sustain mild TBIs, it would be useful to identify those at higher risk of having on-going problems.

It is often assumed that the long term effects of injury may be associated with age (Richardson, 1990a) as well as other factors such as personality and family background (Thomsen, 1989). However, results from studies relating to age and outcome vary. Thomsen (1989) reported that 15-21 year olds tend to have poorer behavioural and emotional outcome than 22-44 year olds, whilst Cifu et al. (1996) found that those over 55 years of age had more impaired behaviour and cognition. When evaluating the effects of age, several factors must be borne in mind. As TBIs are much more common in the younger population, an unselected sample would include few individuals at the extremes of the age range (Richardson, 1990a). As found in the current study, different age groups tend to sustain different types of injuries which may have an effect on outcome. In addition, the pathophysiological response to injury may alter with age. Finally hospital admission protocols may vary depending on the age of the patient.

Most recovery is thought to take place in the first 6-12 months after injury (Jennett and Bond, 1975; Teasdale and Jennett, 1976), although it is believed by some that further improvement does take place in the subsequent years (Dikmen et al. 1983; Thomsen, 1984; Rappaport et al. 1989; Harrison-Felix et al. 1996). The results from the current study indicate that there is no difference in outcome relating to the number of years after injury. However, this must be qualified by emphasising that this study focused on those 5-11 years after injury, when significant improvement was less likely than in the earlier years. It may also indicate that the measures employed are not sufficiently sensitive to detect small changes. However, Corrigan et al. (1998) also found that the majority of areas did not show significant improvement over time.

5.5 SUMMARY

One of the aims of this study was to describe the long term consequences of TBI using a selection of recommended outcome measures. This study would suggest that assessing outcome 5-11 years after injury is a difficult and complex task. Assessment must move away from areas such as physical status and ADL and concentrate on psychosocial outcome and handicap, however there is currently no single measurement tool which is able to comprehensively assess outcome many years after TBI.

The most useful information was provided by the SF-36 which was found to be acceptable to this population in an interview format but it must be noted that a large proportion of patients did require assistance to complete the questionnaire. Although no differences in SF-36 scores were evident between the groups in terms of age or injury severity, the TBI patients did appear to report poorer health for Role Limitations, Physical Functioning and Social Functioning subscales when compared with the general population of a similar age. The study has provided the first UK SF-36 data for a TBI population however further research is required to determine the reliability of the SF-36 in this setting and to investigate the substantial ceiling effects found for some of the subscales.

The CIQ was found to be relatively quick and easy to complete in this study, but as it was only used on half the sample data analysis was limited. Ceiling effects were evident in one subscale, and it would be interesting to explore this further. Another study has found that the CIQ has demonstrated improvement in status over the first five years following TBI (Corrigan et al. 1998). The ERSS was found to be acceptable to the patient population and this research would indicate that the total ERSS score provides a useful guide in determining the likelihood of maintaining employment.

The FIM+FAM was found to be severely limited by very large ceiling effects across its dimensions and therefore would not be recommended as an assessment tool many years after injury. Similarly the subscales comprising the Physical Dimension of the FLP were also subject to large ceiling effects, and as the FLP is a lengthy questionnaire this may affect response rates. Finally the KAS-R1 was not shown to be a useful means of assessing the patient's pre-injury and current neurobehavioural status as it was found to be unwieldy and contain unacceptable items.

Chapter Six

Long term follow up of traumatically brain injured patients by postal survey: Study population and methods

6.1 INTRODUCTION

The majority of studies of TBI patients have used face-to-face interviews as the main method of data collection (Thomsen, 1984; Brooks et al. 1987). The aim of this research was to assess long term outcome of TBI by means of a postal survey. The objectives were firstly to explore the feasibility of collecting data by postal survey in this population, and secondly to describe the self-perceived long term outcome of TBI using the SF-36 and FLP, and to relate this to age, severity of injury and time post-injury.

6.2 STUDY METHODOLOGY

ETHICAL APPROVAL

Ethical approval was gained from the Lothian Research Ethics Committee (Psychiatry/Clinical Psychology Sub-Committee) and Fife Health Board Ethics Committee. Permission to access the CHI, which holds basic information on all residents registered with a GP within the health board, was sought and granted. Access to the deaths register from 1984 to the commencement of the study was also achieved.

STUDY DESIGN

The study design was a retrospective cohort study of TBI patients admitted to the acute neurosurgical unit, Royal Infirmary of Edinburgh (RIE).

PILOT STUDY

A pilot study was undertaken prior to the main survey. This assessed the feasibility of postal data collection in a brain injured population, and the acceptability and response rates to different lengths of questionnaire. The sample (n=122) included neurological admissions to the AAH for rehabilitation over a one year period and diagnoses are presented in Table 6.1. The mean age at the time of the study was 43 years (median=46, range 19-64 years). Seventy-seven patients were male and 45 were female.

Table 6.1 Pilot study diagnoses

Diagnosis	n (%)
Traumatic Brain Injury	45 (37)
Cerebrovascular Accident	21 (17)
Haemorrhagic Brain Injury	16 (13)
Anoxic Brain Injury	5 (4)
Multiple Sclerosis	11 (9)
Other neurological disease	24 (20)
Total	122 (100)

Patients were sent one of three questionnaires, the SF-36, the SF-20 (a precursor of SF-36 containing 20 items) or a 4 item questionnaire devised by the author. Results were based on one mailing. Thirteen letters were returned by the GPO with 'not known at this address'. Of the 109 letters thought to have been received, 70 were returned giving a response rate of 64% for the sample. The response rate by diagnostic group ranged from 20% for the anoxic brain injuries to 73% for those with multiple sclerosis. In the TBI group, 69% responded. The response by questionnaire type ranged from 56% for the SF-36 to 69% for the 4 item questionnaire. The pilot study therefore suggested that a reasonable response rate was possible in the TBI population (Cudmore and Pentland, 1997).

6.3 STUDY POPULATION

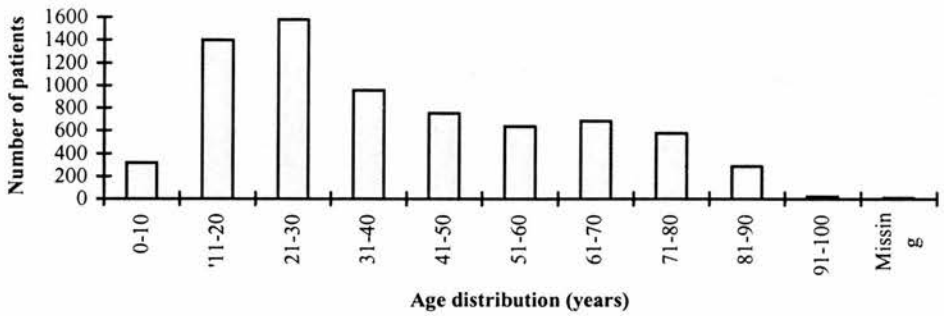
The population comprised individuals within specified age ranges (16-35 years or 50-65 years) therefore covering the peak incidences of TBI. Injuries were sustained within the seven year period, 1984-1990, and both male and female patients were included. The population covered the whole spectrum of injury severity and all patients were resident in Lothian or Fife. During the period of interest, the main neurosurgical unit serving South East Scotland was based at the Royal Infirmary of Edinburgh (RIE). The admission policy was that all TBIs, regardless of severity, were managed in this unit. Permission to access their database of TBI admissions was granted.

Age

Figure 6.1 illustrates the age distribution of admissions to the RIE. Over 7000 TBI cases were admitted over this time period. There was a peak incidence of TBI in young adults,

with a quarter of all patients being aged 16-25 years. A second peak in the elderly is often quoted in the literature, although it is not obvious in this sample.

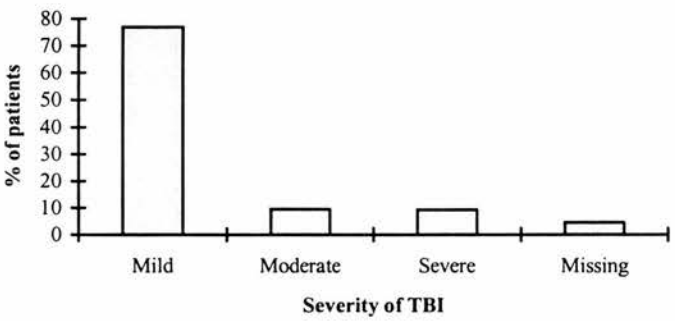
Figure 6.1 Age distribution of admissions to RIE between 1984-1990 (n=7246)



Severity of Traumatic Brain Injury

It was not possible to trace the case notes of the majority of admissions to the RIE, and therefore severity of TBI was based on the GCS score quoted on the database, and categorised as follows: mild (GCS 13-15); moderate (GCS 9-12); severe (GCS 3-8) (Rimel et al. 1981; Rimel et al. 1982). Around three quarters of admissions were classified as mild TBIs (n=5570) with roughly equal numbers being split between the moderate (n=693) and severe categories (n=664) (Figure 6.2). Three hundred and nineteen patients did not have a severity category specified.

Figure 6.2 Severity of TBI admissions to RIE (n=7246)



Year of Traumatic Brain Injury

Table 6.2 provides details of the total number of TBI admissions to the RIE between 1984-1990. The number of admissions per year ranged from 885-1154.

Table 6.2 TBI admissions to RIE from 1984-1990

	Admissions
Year of TBI	n (%)
1984	1154 (15.9)
1985	1125 (15.5)
1986	992 (13.7)
1987	1052 (14.5)
1988	1060 (14.6)
1989	978 (13.5)
1990	885 (12.2)
Total	7246 (99.9)

6.4 EXCLUSION CRITERIA

The sample population was drawn from the 7246 patients admitted to the RIE between 1984-1990 by applying the exclusion criteria detailed below (Table 6.3 and Figure 6.3).

Age at injury

Selected patients were aged 16-35 years or 50-65 years at the time of injury.

Severity of Traumatic Brain Injury

Patients were classified by their GCS score on admission to the RIE in to the three severity categories. If the severity category was not documented the patient was excluded. In order to obtain a representative sample across the injury spectrum, all patients with moderate and severe injuries were included but it was only possible to select a proportion of the mild injuries. A random number generator (using Microsoft Excel Version 7) was used to select a proportion of mild TBI patients.

Area of residence

To assist patient tracing, area of residence at TBI was limited to Lothian and Fife. If no address was available, the patient was excluded.

Deaths

Patients who had died in hospital following the TBI were excluded. Using information from the deaths register, those who had died between discharge from hospital and the start of the study were identified and excluded.

Registration on Community Health Index

Patient details were searched for on the CHI. Those patients who had moved outside Lothian or Fife or were not listed on the CHI were excluded.

Approval from General Practitioner and neurosurgical consultant

Each patient's GP and Neurosurgical Consultant was informed of their proposed inclusion in the study. This allowed relevant details or concerns about involvement to be forwarded to the author.

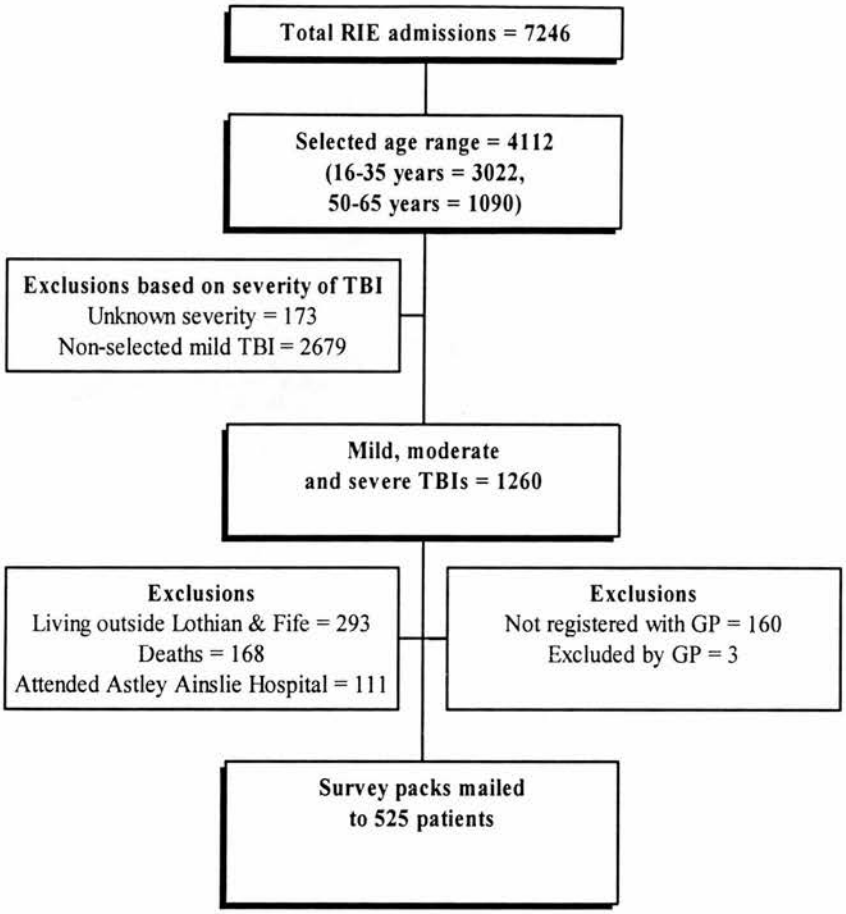
Received rehabilitation at the Astley Ainslie Hospital

Patients who had received rehabilitation at the AAH following their injury were excluded as they were involved in the separate study described in Chapters Four and Five.

Table 6.3 Summary of exclusion criteria for postal survey

Exclusion Criteria	Sample (n=1260)	Mild (n=500)	Moderate (n=385)	Severe (n=375)
Living outside Lothian or Fife at injury	191	0	91	100
Moved outwith Lothian or Fife since TBI	102	65	26	11
Died in hospital after TBI	92	1	9	82
Died subsequently	76	36	27	13
Not registered on CHI	150	98	32	20
Attended AAH for rehabilitation	111	6	35	70
No longer registered with GP	10	0	7	3
Unsuitable for inclusion (GP)	3	1	2	0
Total excluded	735	207	229	299

Figure 6.3 Inclusion and exclusion criteria



After applying the exclusion criteria, 525 patients were available for inclusion and further details of this sample are presented in Chapter Seven.

6.5 DATA COLLECTION METHODS AND HEALTH OUTCOME MEASURES

Two main sources of data were used in this study, a GP rated GOS and self report questionnaires which were mailed to patients.

General Practitioner rated Glasgow Outcome Scale

The GOS was previously described in Chapter Four. General Practitioners were sent a letter asking them to rate each patient on the GOS (Appendix C). Reminders were sent to non-responders after three weeks. Where patients had left the GP practice, the new GP was contacted where possible.

Patient self report questionnaires

Patients were sent a pack in November 1995 which contained the following items:

- letter explaining the purpose of the study and their involvement (Appendix C);
- consent form (Appendix C);
- feedback sheet (Appendix C);
- SF-36;
- a shortened version of the FLP;
- stamped addressed envelope for return of the questionnaires.

A reminder letter was sent to non-responders three weeks later. However, because of a major postal strike which commenced the day after the original packs were sent, many were not delivered. The effect of this became apparent on mailing the reminder letter as a number of patients telephoned to say that they had not received the original package. However, it was not possible to determine which packs had been delivered and which had not. Therefore, in early January 1996 all non-responders were re-mailed with the original package plus a covering letter. No further reminders were sent. Where packs were returned by the GPO as 'not known at this address', the details were re-checked with the GP and the CHI. Any known changes to the address were made and a further pack sent.

The feedback sheet was included in order to determine whether patients had found the questionnaires upsetting or if they had required help. The SF-36 and FLP have been previously described in Chapter Four but in this study an abbreviated version of the FLP

was used which included the 54 items of Psychosocial dimension only. This shortened version was used to avoid discouraging individuals from responding because of the length of the questionnaire. The Psychosocial dimension was chosen over the Physical dimension as it is thought that psychosocial problems tend to predominate in the longer term (Klonoff et al. 1986; Dikmen et al. 1993; Fleming et al. 1997).

6.6 SUMMARY

This chapter has described the study population (n=525) and methods employed in a postal survey of TBI patients, 5-12 years post-injury. The aim of the study was to describe the long term outcome by means of a postal survey. The sample has included all moderate and severely injured TBI patients and a random sample of the mildly injured, admitted to the main neurosurgical unit serving South East Scotland. All patients were aged 16-35 years or 50-65 years at the time of injury and lived within Lothian or Fife. The process of contacting patients and the selected outcome measures have been described.

Chapter Seven

Long term follow up of traumatically brain injured patients by postal survey: Results

7.1 INTRODUCTION

This chapter provides demographic and injury data for the patients in the postal survey including details of age, sex, area of residence, injury severity and cause. This is followed by a comparison of survey responders and non-responders. Details of the global outcome and self report questionnaires are then presented.

7.2 DEMOGRAPHIC DETAILS

AGE, SEX AND AREA OF RESIDENCE

Patients were chosen from two age categories at the time of injury: 16-35 years and 50-65 years. Four hundred and fifteen of the 525 patients (80% of the sample) fell into the younger age group (Table 7.1). The male to female ratio was 4.1:1.0 (80.4% male, 19.6% female). Over 90% of the patients were resident in Lothian.

Table 7.1 Age, sex and area of residence of postal survey sample

	16-35 yr olds (n=415)	50-65 yr olds (n=110)
Age at injury (years)		
Mean (SD)	23.8 (5.5)	56.6 (4.6)
Median	23.0	56.0
Range	16-35	50-65
Age at follow up (years)		
Mean (SD)	32.4 (5.8)	64.9 (4.7)
Median	31.0	65.0
Range	21-47	55-76
Sex		
Male	334	88
Female	81	22
Area of residence		
Lothian	378	97
Fife	37	13

7.3 INJURY DETAILS

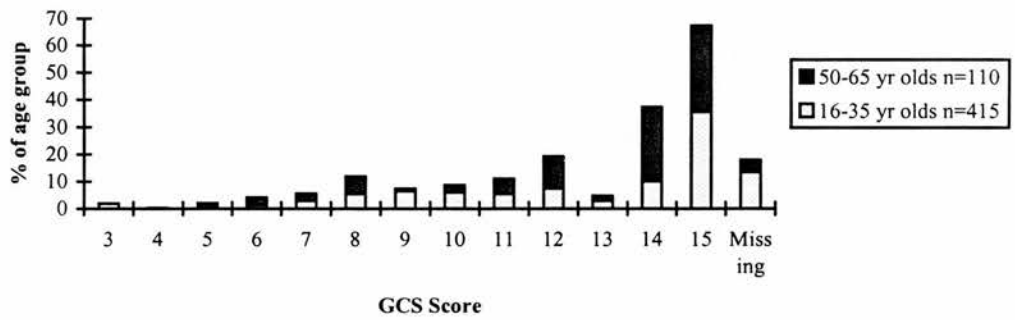
TIME SINCE INJURY

The follow up study was carried out 5-12 years after injury giving a total of 4455 person-years of follow up. The median length of follow up was 8.6 years for the 16-35 year olds (mean=8.6, SD=2.0) and 8.1 years for the 50-65 year olds (mean=8.2, SD=1.8).

INJURY SEVERITY

Injury severity was described by GCS score based upon information available on the RIE database (Figure 7.1). Because of the length of time since injury it was not possible to check the GCS scores manually as hospital case notes had been destroyed.

Figure 7.1 GCS scores by percentage of age group (n=525)



For the 56 cases with unknown GCS score, the severity category assigned during RIE admission was used (Table 7.2). Four cases were GCS 13-15 but as they had undergone neurosurgical intervention, they were classified as moderate injuries as discussed in Section 5.2. The data shows that although there was a tendency for older patients to be less severely injured than younger patients, this was not found to be statistically significant (U=18431.0, p=0.721).

Table 7.2 Severity of TBI by age group

TBI severity	16-35 yr olds (n=415) n (%)	50-65 yr olds (n=110) n (%)	Total (n=525) n (%)
Mild (GCS 13-15)	222 (53.5)	67 (60.9)	289 (55.0)
Moderate (GCS 9-12)	132 (31.8)	28 (25.5)	160 (30.5)
Severe (GCS 3-8)	61 (14.7)	15 (13.6)	76 (14.5)

CAUSE OF INJURY

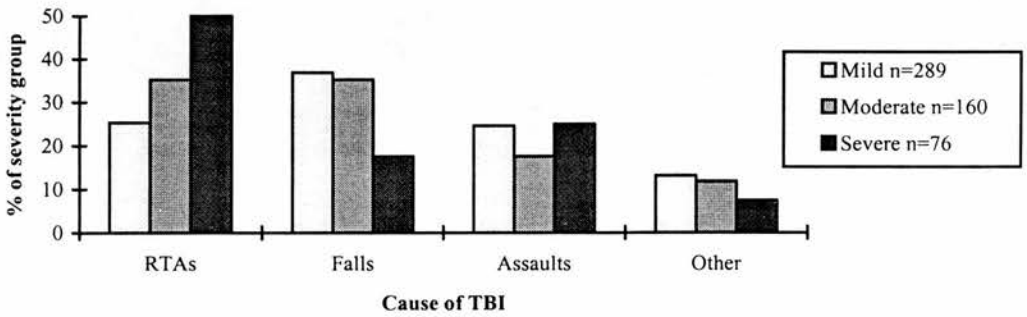
Table 7.3 details the cause of the TBI and reveals that 35.2% were caused by falls, 28.8% by assaults and 27.2% by RTAs. In the younger age group, the three most common causes were assaults (33.7%), RTAs (28.8%) and falls (28.0%), whilst in the older population the corresponding figures were 10.0%, 20.9% and 62.7% respectively.

Table 7.3 Cause of TBI by age group

Cause	16-35 yr olds (n=415) n (%)	50-65 yr olds (n=110) n (%)	Total (n=525) n (%)
RTA-Driver	28 (6.7)	4 (3.6)	32 (6.1)
RTA-Passenger	18 (4.3)	0 (0.0)	18 (3.4)
RTA-Pedestrian	48 (11.6)	16 (14.5)	64 (12.2)
RTA-Motorbike	20 (4.8)	1 (0.9)	21 (4.0)
RTA-Bicycle	6 (1.4)	2 (1.8)	8 (1.5)
Falls	116 (28.0)	69 (62.7)	185 (35.2)
Assaults	140 (33.7)	11 (10.0)	151 (28.8)
Work Accident	1 (0.2)	0 (0.0)	1 (0.2)
Sport/Recreation	21 (5.1)	1 (0.9)	22 (4.2)
Other/Unknown	17 (4.1)	6 (5.5)	23 (4.4)

Figure 7.2 illustrates the cause of TBI by severity of injury and, for simplicity, cause has been divided into four major groups (RTAs, Falls, Assaults and Other). It shows that severe injuries tended to be associated with RTAs, whilst moderate and mild injuries were more commonly as a result of falls. A chi-square test reveals that there was a highly significant relationship between the cause of TBI and severity of injury (χ^2=18.15, p=0.006).

Figure 7.2 Cause of TBI by severity of injury (n=525)

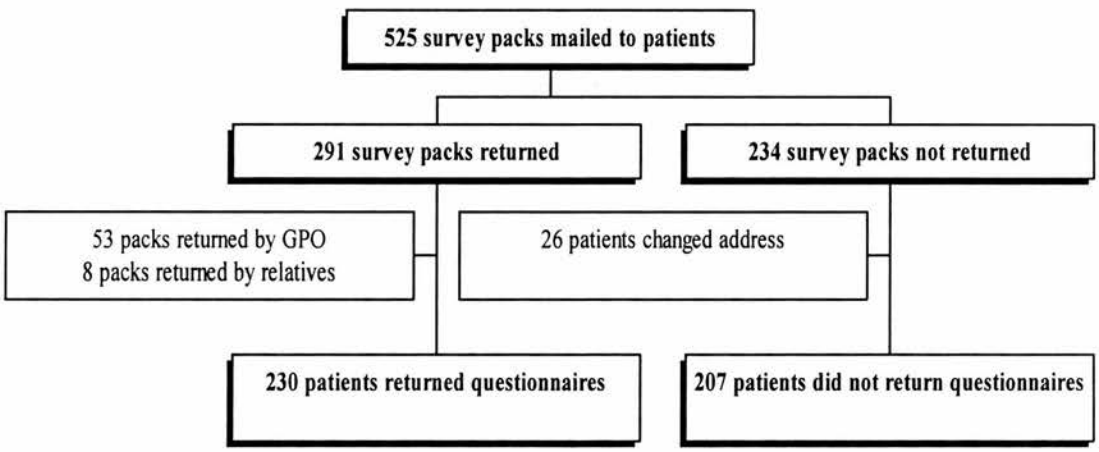


7.4 RESPONSE TO POSTAL SURVEY

RESPONSE RATE

Figure 7.3 illustrates the response to the postal survey. Two hundred and thirty questionnaires were returned by patients following two mailings (175 after first mailing and 55 after second mailing). Eight letters were received from relatives stating that the questionnaire was unsuitable. A further 53 survey packs were returned by the GPO as 'addressee gone away'. The remaining 234 questionnaires were not returned. Given the high number of non-responders, further information was gathered on these individuals near the end of the study allowing time for changes of address and/or GP to be updated on the CHI. This process revealed that a further 26 individuals had not received the questionnaire as they had changed address, (22 had moved within Lothian and four outside Lothian/Fife) and one patient had died at the time of the second mailing (Figure 7.3).

Figure 7.3 Response to postal questionnaire (n=525)



Therefore the response rate has been calculated based upon the 445 patients thought to have received the questionnaire (i.e. excluding those who did not receive the questionnaires but including those where it was thought to be unsuitable) and was found to be 51.7% (230/445).

RESPONDERS AND NON-RESPONDERS

The following section compares the survey responders with the non-responders on various factors. Although it is known that a considerable number of individuals did not receive the questionnaire as detailed in Figure 7.3, the comparison groups are based on the original sample of 525 (i.e. 230 patients who returned the questionnaire and the 295 who did not).

Table 7.4 provides demographic and injury details of responders and non-responders. The mean age of the two groups appears similar and a Mann-Whitney test found no significant difference between responders and non-responders (U=32624.5, p=0.450). There is however a significant difference in response between the sexes, with females more likely to respond than males (χ^2=4.79, p=0.029). When this is further broken down (Table 7.5), it is seen that the 16-35 year old females were significantly more likely to respond than males of this age (χ^2=11.70, p=0.001), but this difference between the sexes was not found in the 50-65 year olds (χ^2=3.28, p=0.070). Response rates were not affected by severity of TBI (U=24909.50, p=0.253) or time post-injury (U=33863.5, p=0.972).

Table 7.4 Characteristics of responders and non-responders

	Responders (n=230)	Non-responders (n=295)
Age (years)		
Injury: Mean (median)	31.4 (25.0)	30.1 (25.0)
Follow up: Mean (median)	39.9 (34.0)	38.6 (34.0)
Sex		
Male	175	247
Female	55	48
GCS score		
Mean (median)	12.2 (14.0)	12.6 (14.0)
Time post-injury (years)		
Mean (median)	8.5 (8.4)	8.5 (8.5)

Table 7.5 Sex of responders and non-responders by age group

	16-35 yr olds (n=415)		50-65 yr olds (n=110)	
	Responders	Non-responders	Responders	Non-responders
Male	128	206	47	41
Female	48	33	7	15

OCCUPATIONAL STATUS OF RESPONDERS

Responders' pre-injury and current occupational status is presented in Table 7.6. In the younger group, there had been a reduction in the number working while the number of unemployed had more than doubled. The situation in the older population is more complicated because many patients had reached retiral age. The majority of individuals in the 'Other' category were in education.

Table 7.6 Occupational status of responders by age group at injury and follow up

	16-35 yr olds (n=176)		50-65 yr olds (n=54)	
	Injury	Follow up	Injury	Follow up
Occupational status	n (%)	n (%)	n (%)	n (%)
Working	131 (74.4)	111 (63.1)	26 (48.1)	7 (13.0)
Retired	0 (0.0)	1 (0.6)	10 (18.5)	34 (63.0)
Unemployed	17 (9.6)	44 (25.0)	14 (25.9)	10 (18.5)
Other	28 (15.9)	20 (11.4)	4 (7.4)	3 (5.6)

7.5 GLASGOW OUTCOME SCALE

Outcome results are discussed with regard to three main factors age, severity of TBI and time post-injury. Because of the number of comparisons undertaken in the analysis, only findings significant at $p<0.01$ or $p<0.001$ level will be discussed.

RESPONSE RATE

The GPs of all 525 patients in the postal survey were asked to rate the patient's current level of residual disability on the GOS (Jennett and Bond, 1975). A very high response rate of 95.8% was achieved following an initial mailing and reminder letter (Table 7.7) and GPs were able to provide a GOS rating on 450 patients (85.7%). Twelve patients had not attended their GP recently and could not be assessed, and a further 41 had left the practice and it was not possible to locate their new GP.

Table 7.7 GP response to GOS survey

	n (%)
Response from GP	
Provided GOS rating	450 (85.7)
Not registered with GP	41 (7.8)
Unable to assess	12 (2.3)
No response from GP	22 (4.2)
Total	525 (100.0)

GLASGOW OUTCOME SCALE SCORES

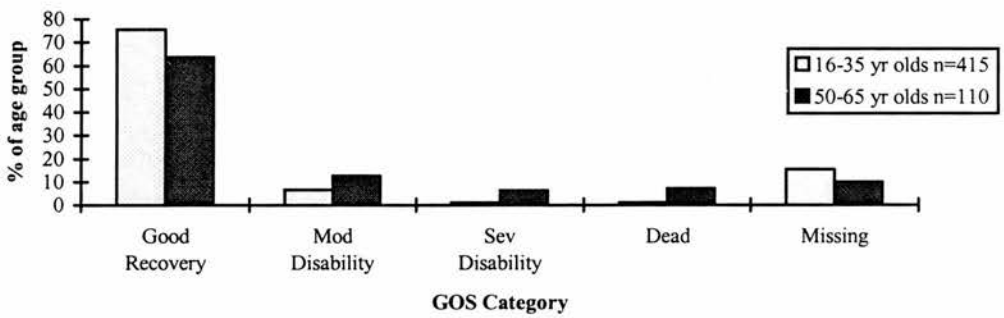
Table 7.8 provides details of the GOS ratings and reveals that of those assessed, 85.3% of patients had made a good recovery, 9.1% had moderate disability, 2.7% severe disability and 2.9% had died. No difference in GOS score was found between responders and non-responders to the postal survey ($\chi^2=3.29$; $p=0.348$).

Table 7.8 GP GOS scores for responders and non-responders

GOS	Responders n (%)	Non-responders n (%)	Total n (%)
Dead	4 (2.0)	9 (3.6)	13 (2.9)
Persistent Vegetative State	0 (0.0)	0 (0.0)	0 (0.0)
Severe Disability	5 (2.5)	7 (2.8)	12 (2.7)
Moderate Disability	23 (11.4)	18 (7.2)	41 (9.1)
Good Outcome	169 (84.1)	215 (86.3)	384 (85.3)
Total	201 (100.0)	249 (99.9)	450 (100.0)

Figure 7.4 illustrates the GOS scores by age groups. The younger group were rated more positively by the GPs, a difference which was found to be highly significant (U=13981.50, $p<0.001$).

Figure 7.4 GP GOS category by percentage of age group (n=525)



No difference was found in GOS score when the sample was split by severity of TBI (Table 7.9) (Kruskal-Wallis H = 1.56, p =0.459) or time post-injury (H=2.66, p=0.914).

Table 7.9 GOS category by severity of TBI

	Severe (n=76)	**Moderate (n=160)**	**Mild (n=289)**
GOS	n (%)	n (%)	n (%)
Dead	1 (1.3)	4 (2.5)	8 (2.8)
Persistent Vegetative State	0 (0.0)	0 (0.0)	0 (0.0)
Severe Disability	3 (3.9)	2 (1.3)	7 (2.4)
Moderate Disability	9 (11.8)	12 (7.5)	20 (6.9)
Good Outcome	52 (68.4)	116 (72.5)	216 (74.7)
Missing	11 (14.5)	26 (16.3)	38 (13.1)
Total	76 (99.9)	160 (100.0)	289 (99.9)

7.6 SELF REPORT QUESTIONNAIRES

In this section data from the feedback sheet included with the questionnaires is presented followed by the SF-36 and FLP data.

FEEDBACK SHEET

In order to assess the acceptability of the self report measures, respondents were asked whether they had required assistance to complete the questionnaires and whether they had found any of the questions upsetting.

Assistance to complete questionnaire

There was a clear difference in the frequency of help required to complete the questionnaire between the two age groups (Table 7.10). Approximately a tenth of the younger group and a third of the older group needed assistance, a difference which was found to be statistically significant (χ^2=10.26, p=0.001). When the sample was divided by severity of TBI, just over a fifth of the moderate and severe groups needed assistance compared with a tenth of the mild group (χ^2=6.45, p=0.040).

Table 7.10 Help required to complete questionnaire by age group and severity of TBI

	Help n (%)	**No help** n (%)	**No response** n (%)
Age group			
16-35 yr olds (n=176)	20 (11.4)	151 (85.8)	5 (2.8)
50-65 yr olds (n=54)	16 (29.6)	37 (68.5)	1 (1.9)
Severity group			
Mild (n=122)	12 (9.8)	106 (86.9)	4 (3.3)
Moderate (n=68)	15 (22.1)	52 (76.5)	1 (1.5)
Severe (n=40)	9 (22.5)	30 (75.0)	1 (2.5)

Questionnaire acceptability

This question was used to determine whether respondents had found items upsetting (Table 7.11). No difference was found between the age groups although approximately a tenth of the population reported that they had found some items upsetting. When divided by severity of injury, over a fifth of the severely injured responding positively compared with less than a tenth of the mild and moderate groups (χ^2=6.44, p=0.040).

Table 7.11 Questionnaire acceptability by age group and severity of TBI

	Upsetting	Not upsetting	No response
	n (%)	n (%)	n (%)
Age group			
16-35 yr olds (n=176)	22 (12.5)	146 (83.0)	8 (4.5)
50-65 yr olds (n=54)	5 (9.3)	45 (83.3)	4 (7.4)
Severity group			
Mild (n=122)	12 (9.8)	102 (83.6)	8 (6.6)
Moderate (n=68)	6 (8.8)	62 (91.2)	0 (0.0)
Severe (n=40)	9 (22.5)	27 (67.5)	4 (10.0)

SHORT FORM 36

Data was coded, and missing or multiple responses re-coded, as directed by the SF-36 scoring manual (Ware et al. 1993).

Completeness of the Short Form 36

In this survey, 181 of the 230 questionnaires returned (78.7%) were fully completed by respondents. The remaining questionnaires had one or more missing or incorrectly completed items. Table 7.12 presents the percentage of patients with fully completed SF-36 questionnaires by age and severity group. Less than half of the older population fully completed the questionnaire compared with almost 90% of the younger group, a difference which was found to be significant at the $p < 0.001$ level ($U=2855.00$). Comparing the three severity categories, a lower percentage of the mild and moderate groups completed the questionnaire compared with the severe group although this difference was not significant ($H=3.26$, $p=0.196$). These completion rates may have been influenced by the amount of assistance required, as a fifth of the moderate and severe population needed help (Table 7.10).

Table 7.12 SF-36 completion rates by age and severity of TBI

Age group	n (%)	**Severity group**	n (%)
16-35 yr olds (n=176)	155 (88.1)	Mild (n=122)	91 (74.6)
50-65 yr olds (n=54)	26 (48.1)	Moderate (n=68)	55 (80.9)
		Severe (n=40)	35 (87.5)

Complete and computable Short Form 36 scales

As mentioned previously, the multi-item nature of the SF-36 allows re-coding of some missing items or multiple responses. Table 7.13 details the proportion of respondents who returned the SF-36 with complete scales, and following re-coding, the proportion with computable scales. The percentage with complete scales ranged from 88.3-97.8% and rose to 91.7-99.6% following re-coding.

Table 7.13 Complete and computable SF-36 scales (n=230)

	Complete scales	**Computable scales**
SF-36 scale	n (%)	n (%)
Physical Functioning (PF)	203 (88.3)	218 (94.8)
Physical Role Limitations (RP)	204 (88.7)	211 (91.7)
Bodily Pain (BP)	224 (97.4)	229 (99.6)
General Health Perceptions (GH)	206 (89.6)	223 (97.0)
Vitality (VT)	223 (97.0)	226 (98.3)
Social Functioning (SF)	225 (97.8)	228 (99.1)
Emotional Role Limitations (RE)	206 (89.6)	211 (91.7)
General Mental Health (MH)	220 (95.7)	225 (97.8)

Short Form 36 scores

Table 7.14 provides details of the mean and median scores for the SF-36 with a higher score indicating better health. Lowest scale scores were found for Vitality and General Health Perceptions whilst the highest scores were recorded for Physical Functioning, Social Functioning and Physical Role Limitation.

Table 7.14 SF-36 scale statistics (n=230)

SF-36 scale	n	Mean (SD)	Median
Physical Functioning	218	74.9 (30.9)	90.0
Physical Role Limitations	211	71.7 (39.7)	100.0
Bodily Pain	229	68.0 (30.6)	74.0
General Health Perceptions	223	57.6 (29.2)	62.0
Vitality	226	54.1 (25.2)	55.0
Social Functioning	228	72.7 (30.1)	87.5
Emotional Role Limitations	211	68.9 (41.9)	100.0
General Mental Health	225	64.9 (23.8)	68.0

Mean Short Form 36 scale scores by age group

Figure 7.5 illustrates the mean scale scores by age group (the abbreviations used are detailed in Table 7.13). For all except Mental Health, the younger population had higher scores than the older group indicating better health. The lowest scores were for Vitality in the younger group and Physical Role Limitation in the older group. Mann-Whitney tests revealed that the older group had significantly poorer health for all but Vitality, Emotional Role Limitations and Mental Health (Table 7.15).

Figure 7.5 Mean SF-36 scale scores by age group (n=230)

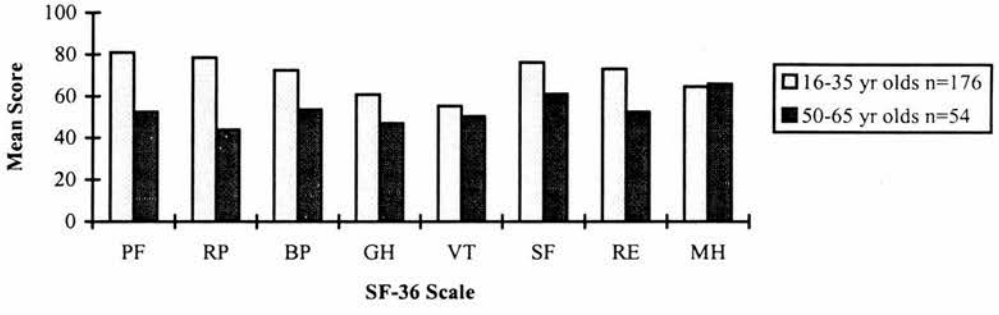


Table 7.15 Difference in SF-36 scale scores by age group

SF-36 scale	U	p value	sig level†
Physical Functioning	1869.00	<0.001	***
Physical Role Limitation	2049.50	<0.001	***
Bodily Pain	3113.50	<0.001	***
General Health Perceptions	3095.50	0.002	**
Vitality	3911.50	0.230	NS
Social Functioning	3363.50	0.002	**
Emotional Role Limitation	2647.00	0.011	*
General Mental Health	4298.00	0.972	NS

† NS=non-significant, *=p<0.05, **=p<0.01, ***=p<0.001

Mean Short Form 36 scale scores by severity of Traumatic Brain Injury

The mean SF-36 scale scores for each of the severity groups are illustrated in Table 7.16. Although the severely injured patients had the lowest scores in each scale there was no consistent pattern between the moderate and mild groups. Only Vitality showed a significant difference between the groups.

Table 7.16 Mean SF-36 scale scores by severity of TBI

SF-36 scale	Mild (n=122)	Moderate (n=68)	Severe (n=40)	p (sig level†)
Physical Functioning	78.1	74.3	67.1	0.112 (NS)
Physical Role Limitation	71.0	80.2	59.9	0.044 (*)
Bodily Pain	67.7	72.9	60.5	0.081 (NS)
General Health Perceptions	59.9	60.1	47.0	0.046 (*)
Vitality	55.5	59.0	41.6	0.001 (***)
Social Functioning	73.4	77.6	62.2	0.045 (*)
Emotional Role Limitation	69.4	75.8	57.0	0.069 (NS)
General Mental Health	66.8	67.5	54.8	0.024 (*)

† NS=non-significant, *=p<0.05, **=p<0.01, ***=p<0.001

Mean Short Form 36 scale scores by time post-injury

No significant differences were found relating to the time since injury.

Distributional characteristics of Short Form 36

To determine whether the range of health states defined by the SF-36 scales was appropriate for TBI patients several years after injury, the percentage of the sample achieving the lowest (floor effect) and highest (ceiling effect) possible scores were calculated (Table 7.18). The full range of the score distribution was observed for all scales except General Mental Health. Substantial ceiling effects were noted for the two Role Limitation scales as well as Physical Functioning, Bodily Pain and Social Functioning. Noteworthy floor effects were observed for the Role Limitations scales (17.5% for RP and 21.8% for RE).

Table 7.17 Distributional characteristics of SF-36 scale (n=230)

	Floor	**Ceiling**	**Range**
SF-36 scale	n (%)	n (%)	(0-100%)
Physical Functioning	6 (2.8)	72 (33.0)	0-100
Physical Role Limitations	37 (17.5)	129 (61.1)	0-100
Bodily Pain	5 (1.7)	79 (34.5)	0-100
General Health Perceptions	7 (3.1)	16 (7.2)	0-100
Vitality	2 (0.9)	4 (1.8)	0-100
Social Functioning	5 (2.2)	92 (40.3)	0-100
Emotional Role Limitations	46 (21.8)	128 (60.7)	0-100
General Mental Health	0 (0.0)	8 (3.6)	4-100

FUNCTIONAL LIMITATIONS PROFILE

Two hundred and thirty individuals completed the abbreviated FLP containing the 54 items which comprise the Psychosocial dimension. A lower score indicates better functioning. For the total sample, the five subscale scores were found to be relatively similar with Sleep and Rest the area of best functioning and Recreation the area of poorest functioning (Table 7.18).

Mean Functional Limitations Profile scores by age group

When the scores are analysed by age group, it is shown that the area of best functioning is Sleep and Rest for the younger group and Emotion for the older group (Table 7.18). Performing Mann-Whitney tests revealed that there were significant differences between the age groups for Recreation and Sleep and Rest (Table 7.19).

Table 7.18 Mean FLP scores by age group

	16-35 yr olds (n=176)	50-65 yr olds (n=54)	Total (n=230)
FLP subscale	Mean (SD)	Mean (SD)	Mean (SD)
Psych Dimension	20.1 (21.0)	20.6 (18.4)	20.2 (20.4)
Social Interaction	19.6 (22.0)	19.4 (19.1)	19.6 (21.3)
Emotion	20.9 (27.3)	15.1 (21.1)	19.5 (26.1)
Alertness	23.3 (30.2)	19.1 (26.7)	22.3 (29.4)
Sleep & Rest	16.1 (19.8)	24.2 (21.1)	18.0 (20.4)
Recreation	20.5 (23.4)	31.8 (26.8)	23.1 (24.6)

Table 7.19 Difference in FLP scores by age group

FLP subscale	U	p value	sig level†
Psychosocial Dimension	4334.50	0.327	NS
Social Interaction	4526.50	0.593	NS
Emotion	4337.00	0.308	NS
Alertness	4422.00	0.414	NS
Sleep & Rest	3427.00	0.001	**
Recreation	3494.50	0.003	**

† NS=non-significant, **=p<0.01

Mean Functional Limitations Profile scores by severity of Traumatic Brain Injury

Table 7.20 illustrates the mean FLP scores in the three severity groups and it is clear that the more severely injured patients have higher scores in each FLP subscale, indicating poorer functioning. However, only Social Interaction has a significant difference ($p<0.01$) between the severity groups (Table 7.21).

Table 7.20 Mean FLP scores by severity of TBI

	Mild (n=122)	**Moderate (n=68)**	**Severe (n=40)**
FLP subscale	Mean (SD)	Mean (SD)	Mean (SD)
Psychosocial Dimension	17.8 (18.8)	19.2 (19.3)	29.3 (24.3)
Social Interaction	16.5 (18.9)	17.9 (19.9)	31.8 (26.3)
Emotion	18.2 (26.2)	17.4 (23.6)	27.2 (28.9)
Alertness	19.4 (28.2)	21.7 (27.3)	32.4 (34.5)
Sleep & Rest	16.1 (17.1)	18.8 (22.5)	22.5 (25.0)
Recreation	21.4 (24.2)	22.5 (24.5)	29.4 (25.7)

Table 7.21 Difference in FLP scores by severity of TBI

FLP subscale	**H**	**p value**	**sig level†**
Psychosocial Dimension	6.75	0.034	*
Social Interaction	10.43	0.005	**
Emotion	4.74	0.094	NS
Alertness	5.64	0.060	NS
Sleep & Rest	1.16	0.561	NS
Recreation	3.40	0.183	NS

† NS=non-significant, *=$p<0.05$, **=$p<0.01$

Mean Functional Limitations Profile scores by time post-injury

No significant differences relating to time post-injury were found for the FLP scores.

Distributional characteristics of Functional Limitations Profile

Table 7.22 describes the distributional characteristics of the FLP. The full range of score distribution was observed for four of the five subscales. Substantial ceiling effects (i.e. a low FLP score) were found for all five of the FLP subscales and a fifth of the sample scored at the ceiling level for the Psychosocial Dimension. Floor effects were not evident.

Table 7.22 Distributional characteristics of FLP (n=230)

	Floor	**Ceiling**	**Range**
FLP subscale	n (%)	n (%)	(0-100%)
Psychosocial Dimension	0 (0.0)	44 (19.1)	0-94.5
Social Interaction	0 (0.0)	70 (30.4)	0-92.9
Emotion	3 (1.3)	104 (45.2)	0-100
Alertness	7 (3.0)	109 (47.4)	0-100
Sleep & Rest	2 (0.9)	85 (37.0)	0-100
Recreation	3 (1.3)	80 (34.8)	0-100

7.7 OUTCOME MEASURES BY GLASGOW OUTCOME SCALE CATEGORY

Kruskal Wallis tests were used to compare the SF-36 and FLP mean scale scores by GOS category (Table 7.23). These revealed that highly significant differences in mean SF-36 scores were found between the GOS categories for Physical Functioning, General Health, Vitality, Emotional Role Limitations and Mental Health. It is interesting that significant results were found across both the physical and mental health scales as this was not so in the interview study in Chapter Four and Five. This may simply be a reflection of the larger sample size in this study or it may relate to the difference in injury severity of the samples. In the FLP, the Psychosocial dimension score, Recreation and Alertness scales showed a significant difference between the GOS categories.

Table 7.23 SF-36 and FLP means by GOS category

	Glasgow Outcome Scale			
	Good Recovery	Moderate Disability	Severe Disability	p value (sig level†)
SF-36 mean scores				
Physical Functioning	77.9	56.8	27.5	<0.001 (***)
Physical Role Limitations	73.4	48.8	75.0	0.046 (*)
Bodily Pain	69.3	46.2	63.2	0.004 (**)
General Health	60.9	32.1	43.4	<0.001 (***)
Vitality	57.3	35.5	63.0	<0.001 (***)
Social Functioning	75.9	58.0	65.0	0.018 (*)
Emotional Role Limitations	73.6	47.0	100.0	0.009 (**)
Mental Health	67.1	49.7	69.6	0.006 (**)
FLP mean scores				
Psychosocial Dimension	18.5	32.2	18.9	0.002 (**)
Social Interaction	17.7	28.4	19.1	0.013 (*)
Emotion	17.6	34.8	16.7	0.029 (*)
Alertness	20.8	38.3	26.8	0.008 (**)
Sleep and Rest	17.5	25.0	14.2	0.042 (*)
Recreation	20.3	40.1	15.1	<0.001 (***)

† *=p<0.05, **=p<0.01, ***=p<0.001

Correlations between Short Form 36 and Functional Limitations Profile

Table 7.24 illustrates the Spearman's rank correlation between the SF-36 and FLP scales. All are found to be negatively correlated as high scores indicate good health on the SF-36 but poor health on the FLP. Correlation coefficients range from 0.38-0.75, with the majority over 0.5, and all were significant at the $p<0.001$ level. As one would expect, the non-physical scales of the SF-36 correlate most strongly with the Psychosocial dimension of the FLP.

Table 7.24 Spearman's rank correlations between SF-36 and FLP scales

	Psycho Dim	**Soc Int**	**Emot**	**Alert**	**Sleep**	**Recreat**
SF-36 scale	r_s	r_s	r_s	r_s	r_s	r_s
PF	-0.53	-0.46	-0.42	-0.38	-0.52	-0.50
RP	-0.57	-0.51	-0.44	-0.47	-0.57	-0.58
BP	-0.60	-0.55	-0.51	-0.47	-0.55	-0.49
GH	-0.71	-0.64	-0.61	-0.60	-0.60	-0.57
VT	-0.70	-0.65	-0.57	-0.57	-0.61	-0.58
SF	-0.71	-0.70	-0.54	-0.54	-0.59	-0.64
RE	-0.63	-0.60	-0.47	-0.50	-0.57	-0.59
MH	-0.75	-0.74	-0.68	-0.59	-0.58	-0.61

7.8 DISCUSSION

STUDY POPULATION

Representativeness

Patients were drawn from all TBI admissions to the acute neurosurgical unit serving South East Scotland. However, the sample is not representative of this population because of the exclusion of individuals who had received rehabilitation or were outwith the age criteria and as only a proportion of those with mild injuries were included. It was felt important to include those with mild injuries as they comprise the majority of hospital admissions whereas many studies concentrate only on the severely injured (Thomsen, 1984; Brooks et al. 1987). Although included in the current study, it must be emphasised that the mildly injured patients are only representative of those who are hospitalised and not all patients who sustain a mild TBI.

Descriptive and injury data

Because of length of time post-injury, it was not possible to verify injury data from clinical notes as most had been destroyed or lost. Therefore the GCS scores quoted are taken from the RIE database and it is acknowledged that these may not have been collected in a standardised manner. With regard to severity classification, PTA data would also have been useful but this was not available. Based on the GCS score, 55.0% of the population were mildly injured, 30.5% moderately injured and 14.5% severely injured. As those who received rehabilitation at the AAH were excluded from the postal study, the proportion of moderate and severely injured patients is much lower than in the interview study described in Chapters Four and Five, where 71% were severely injured. However, the figures are comparable with the sample followed up by Masson et al. (1996) in a community based study in France. Unlike the interview population, no significant difference was found in severity of injury between the younger and older groups and this may relate to the number of mildly injured patients.

Details of the cause of TBI revealed that 35.2% were due to falls, 28.8% assaults and 27.2% RTAs. The breakdown of cause of injury is very different to the interview study, particularly with regard to the percentage of RTAs, but this correlates with the injury severity of each sample. The figures for the postal survey are comparable with those reported for adults under 65 years of age in Scotland by Jennett (1996) (32% assaults, 27% falls and 24% RTAs).

Occupational status

Compared with many studies, the rate of employment at follow up in the younger group is very favourable and it was thought that this might reflect the bias towards the less severely injured in this sample. However, when employment rates were categorised by severity of injury (Table 7.25), very similar percentages were found across the injury groups.

Table 7.25 Occupational status at follow up by severity of TBI

	Mild (n=122)	**Moderate (n=68)**	**Severe (n=40)**
Occupational status	n (%)	n (%)	n (%)
Working	66 (54.1)	32 (47.1)	20 (50.0)
Retired	19 (15.6)	11 (16.2)	5 (12.5)
Unemployed	24 (19.7)	17 (25.0)	13 (32.5)
Other	13 (10.7)	8 (11.8)	2 (5.0)

In a study of moderate and severely injured patients, Sander et al. (1996) reported that by three years only 25% of the sample were employed and 48% were unemployed. Studies of the more severely injured have found unemployment rates ranging from 55-63% (Brooks et al. 1987; Rappaport et al. 1989; Ponsford et al. 1995). More favourable employment rates (70%) were reported by Schalen et al. (1994) at five to eight years post-injury, but this may relate to patient selection criteria as only those who were had made a good recovery or had moderate disability at six months were included. With regard to mild injury, Wrightson et al. (1981) found that all subjects returned to work 0-26 days after injury although a fifth continued to have symptoms at 90 days. However the sample is poorly defined and it is unclear which patients were included in the study, although it appears that the majority did not require hospital admission.

GLASGOW OUTCOME SCALE

Although using GP rated GOS scores is not ideal (Anderson et al. 1993), it was felt necessary to have an external assessment of the patient where possible. Asking a relative or close friend to rate the individual was thought too difficult given the postal format of this survey. The GOS ratings also provided a further comparison between responders and non-responders to the postal survey. The rating by the GP is clearly limited by their knowledge of the patient and a proportion were unable to provide an assessment as the patient had not attended the surgery recently. It is reported that GPs tend to make an overoptimistic assessment of the TBI patient on the GOS compared with a psychologist (Anderson et al. 1993). Jennett et al. (1981) had previously suggested that knowledge of the original injury severity might influence the outcome score assigned. With this in mind, it is interesting and somewhat surprising that no difference in GOS score was found in relation to severity of injury or time since injury although younger patients were rated as having a better outcome than older patients. The limitations of the GOS discussed in Chapter Five, in particular its insensitivity, are clearly important when considering these findings.

SELF REPORT QUESTIONNAIRES

Response rate

Unfortunately the postal survey was hampered by a large national postal strike which disrupted the delivery of the original questionnaire, and resulted in a further mailing to all non-responders. The response rate of 51.7% may be low compared with postal surveys of other patient groups, but it compares well with the few which have been reported in TBI populations who are known to be difficult to follow up (Brooks and Aughton, 1979). For example, Sunderland et al. (1984) studied memory failures in a mixed severity TBI population and achieved a response rate of 53.2%. Postal surveys of the general population have also found low response rates. Dengler et al. (1997) reported a response rate of 62% when studying lifestyle, and Pawlikowska et al. (1994) achieved a response rate of 48.3% when studying fatigue and psychological distress.

The current survey found that females were more likely to respond than males especially in the younger sample. This pattern has also been reported by Dengler et al. (1997) who showed that non-responders to postal surveys were more likely to be male, aged 16-34 years and from a lower income bracket. Similarly others have reported a low response rate in those with poor education and lower socio-economic group (Sheikh and Mattingly, 1981). Prior to the survey it was thought that the mildly injured patients might have been less

motivated to respond than the severely injured, but this was not the case. However Parker et al. (1998) found that response was adversely affected by cognitive and physical disability in older patients.

Feedback sheet

A significant difference in the need for assistance to complete the questionnaires was found between the age groups, with help required by 11.4% of the younger group and 29.6% of the older group. Although this latter figure is high, Dorman et al. (1998) reported that 48% of patients 15 months after a stroke required help to complete the SF-36.

Short Form 36

Completeness of data

One aspect of interest in this thesis was the completeness of SF-36 data collected from a TBI population, especially when compared with other patient groups. In the current study, computable scales ranged from 91.7% (Physical and Emotional Role Limitations) to 99.6% (Bodily Pain). These rates are poorer than results from a postal survey of the general population in the US (McHorney et al. 1994a) where the range of computable scores was 97.6% (Emotional Role Limitations) to 99.8% (Bodily Pain and Social Functioning). The lower percentages reported in the current study may reflect cognitive and communication difficulties.

Although the overall scale completion rates were satisfactory, the older population were significantly less likely to fully complete the questionnaire (Table 7.12). Brazier et al. (1992) reported that the percentage of missing SF-36 data in their postal survey was significantly associated with age, although the extent of missing data is not specified. Some studies of older patients suggest that a self administered SF-36 is not suitable for the elderly population as although response rates are good, actual completion rates are low (Parker et al. 1998). O'Mahoney et al. (1998), in a postal survey of older stroke patients, reported that completion rates for some scales were as low as 73%. They suggested that data completeness may have compromised the validity of their results because of non-response bias and therefore reduced their ability to generalise results. They concluded that the SF-36 was not suitable for administration in a postal format to the older stroke population. However, use of the SF-36 in the elderly has been found to be satisfactory in an interview setting (Lyons et al. 1994).

The extent of missing data might also reflect respondents' understanding, acceptance, and perception of relevance of the survey (Dorman et al. 1998; O'Mahoney et al. 1998). The current survey found that the two Role Limitations scales had low computable scale rates for the older patients (Table 7.26), and this may be due to a lack of perceived relevance to this sample. The low rates for these scales, and the need for assistance by 30% of the older population, would suggest that the SF-36 is not suitable for an older TBI population in a postal format. Consideration must also be given to the finding that over a fifth of the severely injured population found some items upsetting.

Table 7.26 Computable SF-36 scales by age group

	16-35 yr olds (n=176)	**50-65 yr olds (n=54)**
SF-36 scale	n (%)	n (%)
Physical Functioning	172 (97.7)	46 (85.2)
Physical Role Limitations	170 (96.6)	41 (75.9)
Bodily Pain	176 (100.0)	53 (98.1)
General Health Perceptions	173 (98.3)	50 (92.6)
Vitality	176 (100.0)	50 (92.6)
Social Functioning	175 (99.4)	53 (98.1)
Emotional Role Limitations	171 (97.2)	40 (74.1)
General Mental Health	176 (100.0)	49 (90.7)

Dengler (1997) looked at item non-response in a postal lifestyle survey and found that 15% of the sample failed to complete the questionnaire. A higher level of item non-response was associated with female gender, 55-70 year age range, lower levels of education, lower socio-economic status and poorer health. In the current study there was no difference in completion rates between the severity groups which is surprising but may relate to greater need for assistance in the severely injured sample.

Short Form 36 scale scores

In this sample, poorest health was indicated for Vitality and General Health. When divided by age group, the older population reported lower levels of health in seven of the eight SF-36 scales and highly significant differences were found for Physical Functioning, Physical Role Limitations, Bodily Pain, General Health and Social Functioning. This may simply reflect changes relating to ageing rather than an effect of the TBI as it is known that age is associated with lower scores on the SF-36 (Jenkinson et al. 1993). Only Vitality showed a significant difference between the severity groups and no differences were found relating to time post-injury. A recent study of TBI in 15-19 year olds (Colantonio et al. 1998) also found no difference in SF-36 scale scores between the mild and more severely injured groups. Lowest scores were found for Mental Health.

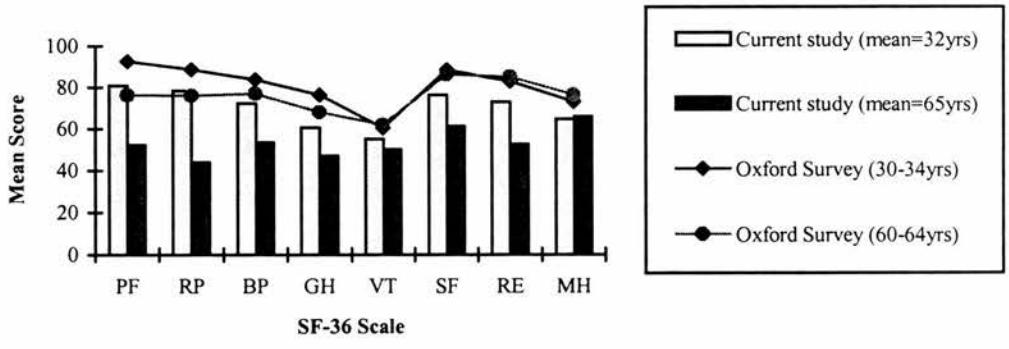
Distributional characteristics of the Short Form 36

Substantial ceiling effects were noted for five of the SF-36 scales in this sample and noteworthy floor effects were observed for the Role Limitations scales. Ceiling effects have previously been shown for the Role Limitations scales in both general and stroke populations (McHorney et al. 1994b; O'Mahoney et al. 1998). These ceiling and floor effects suggest that the SF-36 is inadequate on its own for assessing outcome following TBI.

Normative and Traumatic Brain Injury Short Form 36 data

Figure 7.6 presents SF-36 data for the current sample alongside normative UK data (Oxford survey) (Jenkinson et al. 1996) from two similar age groups which are illustrated by the line graphs. For the similar age groups, the TBI sample have lower scores than those in the general population.

Figure 7.6 Normative and TBI data for SF-36 scales by age group



Note: Oxford survey provides normative data for the UK

Comparison between Short Form 36 scores for interview and postal surveys

Table 7.27 presents the mean scores for the SF-36 scales for the interview and postal surveys in this thesis. Three of the eight scales (Physical Functioning and the two Role Limitations scales) have lower mean scores indicating poorer health for the interview sample, but the remainder of the scores are relatively similar. These findings may relate to the difference in severity of the samples or may be due to the mode of administration which is also known to affect the scores. McHorney et al. (1994a) found that poorer health was reported by mailed respondents compared with those who were interviewed by telephone. This difference is thought to relate to the greater privacy afforded by the mailed survey.

Table 7.27 SF-36 scale means for interview and postal study

	Interview (n=72)	**Postal (n=230)**
SF-36 scale	Mean (SD)	Mean (SD)
Physical Functioning	64.5 (29.8)	74.9 (30.9)
Physical Role Limitations	54.2 (42.2)	71.7 (39.7)
Bodily Pain	75.4 (28.7)	68.0 (30.6)
General Health Perceptions	56.6 (27.0)	57.6 (29.2)
Vitality	57.7 (24.6)	54.1 (25.2)
Social Functioning	66.7 (30.0)	72.7 (30.1)
Emotional Role Limitations	57.4 (45.2)	69.0 (41.9)
General Mental Health	65.0 (23.7)	64.9 (23.8)

Confidence intervals for individual's Short Form 36 scores

Users of the SF-36 have attempted to interpret scores for individual patients and one concern is how confidently an observed score can be equated with the 'true' score (Ware, 1995). It is possible to calculate the standard error of measurement (SEM) which is an indicator of the amount of 'noise' in repeated assessments and relates to the size of the confidence interval. To date this has not been reported for the SF-36 with a TBI sample. The SEM can be calculated from the following formula: $SEM=SD_t\sqrt{(1-r_{tt})}$, where SD_t is the standard deviation for the score and r_{tt} is the reliability coefficient (Cronbach's coefficient α). Cronbach's coefficient α, a measure of internal consistency, was calculated for each of the eight scales in this study (Cronbach, 1951) (Table 7.28). A low coefficient α (below 0.5) indicates that items in the scale do not come from the same conceptual domain (Bowling, 1997a). In this study, coefficient α was found to range from 0.81 for Social Functioning to 0.95 for Physical Functioning.

Table 7.28 Cronbach's coefficient α for SF-36 scales

SF-36 scales	coefficient α
Physical Functioning	0.95
Physical Role Limitations	0.90
Bodily Pain	0.94
General Health Perceptions	0.90
Vitality	0.86
Social Functioning	0.81
Emotional Role Limitations	0.89
General Mental Health	0.87

The SEM for each of the SF-36 scales for this sample is shown in Table 7.29. For example, the SEM for Physical Functioning is 6.9, which is the standard deviation of scores that would be expected from repeated assessments of the same patient. To determine the confidence interval for an individual score, the bell shaped curve of normal distribution is referred to.

Table 7.29 Standard error of measurement for SF-36 scales

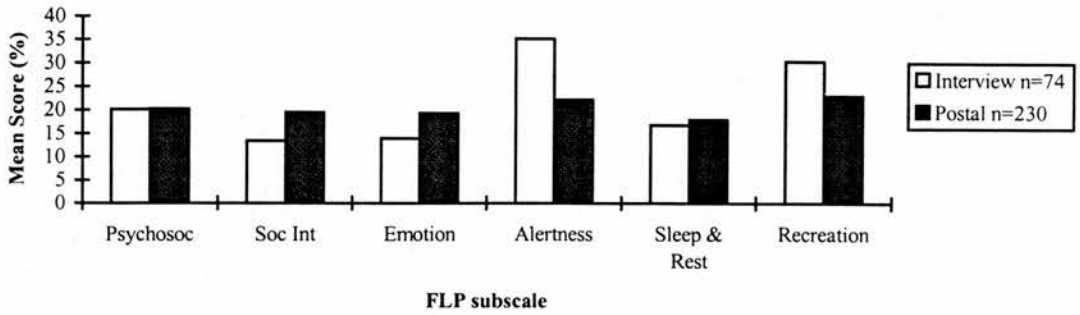
SF-36 scale	SEM
Physical Functioning	6.9
Physical Role Limitation	12.6
Bodily Pain	7.5
General Health Perceptions	9.2
Vitality	9.4
Social Functioning	13.1
Emotional Role Limitation	13.9
General Mental Health	8.6

Functional Limitations Profile

It is not possible to assess the completeness of data for the FLP as items are only ticked if the patient agrees with the statement. Two of the scales (Sleep & Rest and Recreation), but not the overall Psychosocial dimension, had significant differences between the age groups with the younger group reporting significantly better functioning. The less severely injured population reported better functioning for the Social Interaction scale but no other significant differences were found between the severity groups or relating to time post-injury.

Figure 7.7 illustrates the scores for the Psychosocial dimension of the FLP for the interview and postal surveys. There was no consistent pattern of response between the two samples, although the scores for the total dimension were equal. Normative data for the FLP is not available, although total scores for a healthy population are thought to average around two or three (Bowling, 1997b). The scores for both samples in this study are clearly higher than this level.

Figure 7.7 Interview and postal FLP scores



7.9 SUMMARY

This survey achieved a comparable response rate to other postal surveys of the TBI population. Significant differences were found between age groups for five of the eight SF-36 scales, but for only one scale between the severity groups. Two of the FLP subscales had significant differences between the age groups and one between the severity groups. The relatively high rate of missing data for the SF-36 and the need for assistance amongst the older population would suggest that this group found the SF-36 difficult to understand or not relevant to them. It is therefore suggested that the SF-36 is not suitable for use in the postal format for older TBI patients. It does appear useful in the younger population, but requires further investigation.

Chapter Eight
Conclusions

8.1 INTRODUCTION

Evaluation of the outcome of TBI presents several challenges. The definition and classification of TBI was outlined in the first chapter of this thesis together with a brief description of the pathological mechanisms involved. In those who survive the initial life threatening stages, the nature of the damage which has occurred in a particular individual is identified partly by radiological investigations but is primarily a clinical exercise. Thus the initial outcome is described on the basis of such clinical findings.

As the brain controls all other bodily functions as well as being the centre of cognition, emotion and behaviour, damage to it may result in a complex range of impairments. This makes measurement of outcome difficult. There is uncertainty about what aspects of disturbed brain function should be measured, when it is most appropriate to do so and how and by whom it should be done. These factors contribute to the lack of robust epidemiological data on TBI which has been discussed in Chapter Two.

The aim of the research described in this thesis was to attempt to measure outcome of TBI in a longitudinal way. The first approach was to use the recently developed EHIEC as a comprehensive tool which was based on the ICIDH model. When this proved an unwieldy and inappropriate instrument, an alternative method using a group of standardised measures was used. The following sections discuss these findings and the limitations of both methods.

8.2. COMPREHENSIVE SINGLE MEASURE APPROACH TO OUTCOMES ASSESSMENT

The majority of measures tend to focus on a particular area of outcome, for example ADL or cognitive status, and few attempt to provide a single, comprehensive assessment tool. Most of the more commonly recommended multidimensional tools, such as the Disability Rating Scale (DRS) (Rappaport et al. 1982), Patient Evaluation Conference System (PECS) (Harvey and Jellineck, 1981) and the FIM+FAM (Keith et al. 1987; Hall et al. 1993) have originated in the United States. The European Brain Injury Society defined one of its aims as the development of a simple, specific and reliable measure, suitable from the time of injury for several years which would comprehensively assess a TBI patient (Truelle et al. 1990; Truelle and Robert-Pariset, 1990). This thesis has provided the first review of this measure, the EHIEC.

The conclusions about the EHIEC have been drawn from the study described in Chapter Three and the limitations of this research must be acknowledged. Recruitment for the study took place over 12 months, and 47 patients discharged from a rehabilitation unit following a recent TBI were eligible for inclusion. The sample size was therefore relatively small although comparable with many other single centre studies of this population (Thomsen, 1984; Rappaport et al. 1989; Colantonio et al. 1998). Only a proportion of the sample were available for follow up at 15 months post-injury and this is a recognised and common difficulty with the TBI population (Brooks and Aughton, 1979; Rappaport et al. 1989; Masson et al. 1997). The EHIEC was used as the main method of data collection although this was supplemented by FIM+FAM data which was routinely collected in the rehabilitation unit. Further outcome measures were not used as the EHIEC itself requires a lengthy assessment period and patients were recruited during a time of active rehabilitation and may have been involved in other studies.

Having acknowledged the limitations of the study, it is clear that the current version of the EHIEC does not fulfil its goals. Although it does have some potentially useful sub-sections, it was generally found to be cumbersome to use without sufficient clinical utility to become the measure of choice for the TBI population (Cudmore and Pentland, 1996). In addition, published data on the reliability and validity of the EHIEC is scant (Truelle et al. 1992; Truelle, 1993), and this is a recognised problem with many other outcome measures (Frattali, 1993). Frattali (1993), following a review of available functional assessment measures concluded that there was no single tool acceptable to providers, consumers, researchers, policy-makers and payers. The current research would suggest that the EHIEC is also an inadequate means of comprehensively assessing the TBI patient.

8.3 MULTIPLE MEASURES APPROACH TO OUTCOMES ASSESSMENT

Because of the recognised inadequacies of relying on a single measure to assess outcome, the use of multiple measures was also explored. Chapters Four to Seven describe their use in the assessment of long term outcome of TBI. Difficulties in using multiple measures in assessment are discussed in the following sections.

DIFFICULTIES WITH THE MULTIPLE MEASURE APPROACH

Many studies employ more than one measure to assess outcome (Klonoff et al. 1986; Corrigan et al. 1998). Although this may allow a wider variety of aspects to be addressed, it can be difficult to find measures which are complementary but avoid item repetition. For example, in the current study emotional health status was determined by both the SF-36 and FLP, albeit from different angles. It is also important to consider the overall time required for assessment with multiple measures, particularly in a TBI population as subjects may have attentional deficits and be subject to fatigue.

In order to allow comparison between studies, it is necessary to use some common measures of outcome. In the field of TBI, the GOS is probably the most widely quoted measure and its inclusion in all studies is recommended (Clifton et al. 1992). It is quick and easy to complete but provides only a global score of outcome, is relatively insensitive to change in status and provides little detail on the nature of disability. The current research found that severity of TBI was not strongly correlated with GOS score and it may be that many years after injury it is not a useful measure of outcome.

> 'functional status measures focus more on functional limitations than on handicapping environmental factors that prevent consumers from living independently'
>
> (Frattali, 1993)

This research has attempted to look at outcome from the perspective of the patient as well as the carer and researcher. However, functional assessment for example, is rarely addressed from the perspective of the patient (Frattali, 1993). It is often necessary to use separate measures to assess disability or handicap. This research used the FIM+FAM primarily to assess disability and the ERSS and CIQ to assess handicap. Although the multiple measure

approach to assessment has its limitations, it would at present appear preferable to using a single measure, as it allows a variety of known and recommended measures to be combined.

DIFFICULTIES WITH LONG TERM ASSESSMENT

The majority of TBI studies have focused on the early months following injury and few have looked beyond the first two years. Those that have, for example Thomsen (1984), Brooks et al. (1987) and Rappaport et al. (1989), have tended to concentrate on the more severe end of the injury spectrum. This thesis has explored long term outcome, irrespective of injury severity and the difficulties in assessing patients many years after injury are discussed below.

Length of follow up

Patients were assessed 5-12 years after TBI and all had sustained injuries between 1984-1990. The earlier date coincided with the formal establishment of rehabilitation at the AAH, and the end date of 1990 allowed at least five years between injury and assessment. Because of the length of time after injury, patients were not under follow up from other studies. However, one difficulty was the lack of available assessment data from the time of injury other than basic details relating to severity, and this is common in many other studies (Klonoff et al. 1986; Rappaport et al. 1989; Masson et al. 1997).

Representativeness of sample

Obtaining a representative patient sample is very important for any study but can be difficult with the TBI population as subjects may have changed address, died or be unwilling to be followed up (Brooks and Aughton, 1979; Masson et al. 1997). However, a response rate of 71% was achieved in the interview study and responders and non-responders were found to be similar in terms of age and injury severity. Two age groups of patients were chosen to coincide with the peak incidences of TBI, however it may have been more informative to have included all adult TBI admissions. Nevertheless, within these age ranges those interviewed were representative of admissions to the AAH following TBI.

In the postal survey, patients of the same age and length of time post-injury as in the interview study were selected, although they had not attended for rehabilitation. All TBIs, irrespective of severity, were included but because of the large numbers of mildly injured patients only a representative sample of this group was taken. A relatively low response

rate of 51.7% was achieved for the postal survey however this is comparable with the few other postal surveys which have been undertaken in this population (Sunderland et al. 1984). Although just over half the patients returned the questionnaire, response was not affected by severity of TBI or time post-injury. As in most surveys, females were more likely to respond than males (Dengler et al. 1997). Therefore results from the postal survey can be generalised to hospitalised TBI patients who have not attended for rehabilitation, but it must be borne in mind that the sample was biased towards the more severely injured. A revised study design might have included a nested interview study within the larger postal survey. This would have allowed all TBI patients from South East Scotland, regardless of rehabilitation status, to be included in the total sample thus permitting equivalent groups to be either interviewed or involved in the postal survey.

Relationship between Traumatic Brain Injury severity and long term outcome

Although the current research has attempted to study outcome and relate this to injury severity, this is a complex area particularly as time progresses. Many years after injury, it may be impossible to separate the impact of the TBI from other life events on specific symptoms or problems (Brooks et al. 1987; Whalley Hammell, 1994; Masson et al. 1996). Descriptive studies are able to report and explore findings but are not able to determine cause and effect. Nevertheless outcome measures such as the SF-36 which have been used in many patient populations, and have published normative data, do allow some comparison between groups.

8.4 REVIEW OF OUTCOME MEASURES

MEASUREMENT OF HEALTH STATUS

In general, there are two types of instrument used in the measurement of health status. The first provides a single global score of well-being where all items can be summed into a health index, and the second involves the measurement of a number of health dimensions which can be displayed as a health profile. Which method is most useful depends on the purpose of the assessment. Health profiles tend not to be summed into a single figure, but may give greater insight into particular areas of health and have been the focus of this thesis. There has been a proliferation of health status profiles over recent years but the search for a simple, short and psychometrically sound instrument which measures the

important aspects of subjective well being continues. It has been suggested that the ideal tool would be:

> 'the clinical equivalent of the Swiss army knife, something small and easily taken into the field, with enough blades and attachments to fit any number of circumstances that may arise'
>
> (Kane, 1987)

However, the majority of instruments do not meet these criteria. In addition to the SF-36 and SIP/FLP reported here, the Nottingham Health Profile (NHP) (Hunt et al. 1985) and the Dartmouth COOP charts (Nelson et al. 1990) are commonly reported generic health measures. The NHP has been widely used and is short and easy to complete, however it was developed to tap only the severe end of ill-health and therefore produces highly skewed data. The COOP charts were designed primarily for use in clinical practice and not with samples or populations, and it is thought that the pictorial content of the charts may influence subject response (McHorney and Ware, 1992).

Short Form 36

The SF-36 is a short generic outcome measure which has been found to be acceptable to many different patient groups. It has been shown to be psychometrically sound, produce high response rates and be more sensitive to lower levels of ill-health than the NHP (Brazier and Jones, 1992; Jenkinson et al. 1993; McHorney et al. 1993). At the time of this research, there were no reports of the SF-36 being used with a TBI population. Since then, three papers have been published although only one by Colantonio et al. (1998) reports detailed data on the SF-36. She studied a group of 15-19 year old patients five years after TBI, and reported that Mental Health was the area of lowest perceived health. She found no difference between the mild and more severely injured patients but acknowledged that a larger, prospective study was required. The other two studies by Brenneman et al. (1995) and Corrigan et al. (1997) provided few details on the SF-36.

The current research found significant differences between the age groups for the majority of SF-36 scales in the postal, but not in the interview study and this may relate to sample size. Many studies of TBI are based on small numbers of patients (Thomsen, 1984; Colantonio et al. 1998) and it may be that larger studies, possibly multi-centred, would be required to provide significant results. Few differences were found relating to severity of injury and none relating to time post-injury. It is interesting that injury severity did not have more influence on the results and there may be several reasons for this. It is possible that in

the longer term, the degree of disability and handicap across the injury spectrum may converge, although impairment may still be greater in the severely injured. The GCS, which was the only measure available to assess severity in this sample, may be an inadequate means of predicting long term outcome. This finding agrees with Corrigan et al. (1998), who concluded that long term outcome could not be predicted from pre-morbid characteristics, injury severity or initial functional ability. Finally, measures such as the SF-36 may not be sufficiently sensitive to detect differences in this population.

This thesis would suggest that it is possible to use the SF-36 in a TBI population although one or two problems ought to be highlighted. As with any patient sample, levels of missing data are greater when the SF-36 was completed by postal survey compared with an interview setting. In the postal survey, higher levels of missing data were found with the TBI sample than are reported for the general population (McHorney et al. 1994a). Overall the completion rates in the postal survey were acceptable although the level of missing data in the older population was significantly greater than in the younger group, and therefore use of the SF-36 in the older TBI population must be questioned. Other studies have found similar results in an older stroke sample and have suggested that the SF-36 may only be suitable in an interview situation (Lyons et al. 1994; O'Mahoney et al. 1998). The large ceiling effects found are also of concern as degrees of improvement would go undetected. This finding has been previously reported and is thought to be partially related to the emphasis on limitations of functioning (Anderson et al. 1993). Although not evident in this research, the SF-36 has been criticised for floor effects in severely ill populations (Kurtin et al. 1992).

Although the SF-36 is relatively quick to complete, the originators of the questionnaire have recently introduced a 12 item health survey (SF-12), and a UK version is also being developed (Jenkinson and Layte, 1997; Jenkinson et al. 1997). This may prove useful in the TBI population where attentional deficits are common. It may also be worth investigating whether the ceiling effects which were evident in this research with the SF-36, were equally problematic with the SF-12.

Functional Limitations Profile

The FLP/SIP is one of only a few health profiles which allows the calculation of an overall score, and has been subject to extensive reliability and validity analyses. In the interview study, the full version of the FLP was administered by the author. The majority of subscales were found to be relevant to patients. However, because of the length of the questionnaire, only items in the Psychosocial dimension were included in the postal survey in an attempt to improve response rates. Significant differences were found in FLP scores between the age groups in both interview and postal studies. As previously noted, it was not possible to compare FLP scores from the current study with SIP scores from previous research because of differences in item weightings and summary scores, and this limits its use. Work has been done to produce a shortened version of the SIP (SIP-68) which includes items from all categories (Bruin et al. 1994; Post et al. 1996) but its psychometric properties are yet to be fully established. There is also concern over the sensitivity of the original measure in detecting small changes in functioning which is an important feature of a health status questionnaire. Overall the FLP was found to be relatively easy to complete by patients and the Psychosocial dimension was found to be most relevant to the TBI population.

OTHER OUTCOME MEASURES

In the interview study, other outcome measures were also used including the FIM+FAM, ERSS, CIQ and the KAS-R1. The use of these measures has been discussed in Chapter Five but in summary the CIQ, and to a lesser extent the ERSS, were found to be potentially useful in the long term assessment of the TBI patient whilst the FIM+FAM and KAS-R1 were found to have serious limitations.

The CIQ, developed specifically for the TBI population, was found to be quick, easy to complete and score, and addressed a range of areas relevant to the TBI sample in the community. Its drawbacks include difficulty in comparing the current and pre-injury status and concerns over its ability to monitor patients clinically (Dijkers, 1997). In the present study, large ceiling effects were noted for the Home Integration scale. Before the CIQ is used more widely, its inter-rater reliability needs to be further explored. The ERSS was acceptable to patients and the overall score was found to be useful in determining the likelihood of maintaining employment. Two of the subscales however had notable ceiling effects which may limit their usefulness in exploring longer term outcome. The FIM+FAM, although very useful in the early phases of recovery, was found to have ceiling effects across its dimensions. It is therefore concluded that this measure is insensitive and of

limited use several years after injury. Using a measure at the wrong phase of recovery, may jeopardise the validity of an otherwise valid scale (Hall et al. 1996).

In the interview study, relatives were asked to rate the patient on the SF-36 and the KAS-R1. Although use of the SF-36 in this way has not been previously reported, it was felt to be a useful addition to this study. The SF-36 completed by the relative had relatively little missing data, although the two Role Limitations scales had the lowest percentage of computable scores which would indicate that these areas had been most difficult to complete. A comparison of the grouped SF-36 data for patients and relatives revealed that correlations between scores were relatively weak throughout. Because this is not a recommended method of data collection, results must not be over-interpreted but may justify further investigation. The KAS-R1 questionnaire was not found to be useful because of its length, content and administration. Relatives were unable to answer some items which they felt were irrelevant or unacceptable. Asking for a pre-injury as well as post-injury score was also problematic with some respondents misunderstanding the instructions.

8.5 SOURCE OF INFORMATION

The patient, relative and interviewer all contributed to assessment of the patient in this research. Different types of information were collected from each source, and, particularly for the long term follow up studies the patient's perception of his health status was thought to be very important. However, it was not always possible to obtain a view from the patient, and as shown in Chapter Five more than half the sample were unable, or required help, to complete the SF-36. It is recognised that self report will be limited by cognitive impairment and lack of insight (Krefting et al. 1992), and although the patient's own view may not always be the most accurate, it may often be the most crucial.

> 'it is the subjective impairment which represents distressing reality for these patients and dictates their psychosocial adjustment'
>
> (Tyerman and Humphrey, 1984)

The decision of whether to use the patient or a proxy to provide information is clearly difficult and is not only an issue in the field of TBI but also in dementia or terminal illness. The comparability of information from a subject and proxy has been assessed in several studies. Epstein et al. (1989) looked at a variety of areas including functional, emotional and overall perceived health, social activity and satisfaction with medical care. Subjects were aged 65 years and over and drawn from the community and therefore represented a relatively healthy population. The proxies, who were close relatives, were asked to respond as they thought the subject would, rather than for their own opinion of the subject. Correlations between subjects and proxies were very high for the health status measures but low for emotional health and satisfaction with medical care. Higher correlations were found when the subject had better health and was in more frequent contact with the proxy.

Within the patient population, Magaziner et al. (1988) studied the comparability of information between elderly patients with fractured hips and proxies on measures of health and functional status. Poorest agreement between scores was found for the less concrete, less observable behaviours and activities and where the subject had cognitive impairment. The quality and completeness of pre-morbid data was dependent upon the amount of contact between the subject and proxy prior to the event. When studying TBI patients, McKinlay and Brooks (1984) suggested that there are systematic differences between patient and relative reports of outcome. They found a similar pattern to Magaziner et al. (1988) with good agreement for physical and sensory difficulties, modest agreement for cognitive

difficulties, and poor agreement for emotional and behavioural changes. Sbordone et al. (1998) reported that somatic problems were more reliably identified by TBI patients than by family members but that the opposite was true for cognitive emotional and behavioural complaints.

The effects of illness, or in this case TBI, on a patient's ability to rate their own health is a complex area. It is difficult to determine which rating is most accurate or most useful, and as has been highlighted, no source of information is ideal. The source used must be guided by the timing and purpose of assessment, and as time post-injury increases, self report may become more appropriate (Levin et al. 1987). This research has shown that it is possible to collect data from the majority of TBI patients several years after injury, although help may be required. Obtaining data from a proxy has been poorly researched and there are few psychometrically sound measures available designed for this purpose.

Evaluation of change in status

Having used the KAS-R1 in an attempt to evaluate change in status, it raises the issue of how one should look at change in the patient from their pre-morbid state. The vast majority of patients will not have undergone tests of cognitive, emotional or behavioural functioning prior to the injury, and therefore directly comparable information is not available. If assessment is to be undertaken by someone other than the patient, it is clearly necessary for this person to have known the patient well both before and after the injury. Comparisons become more difficult as time since injury increases as memories of the patient may become less accurate, or the patient may now live with a new partner who did not know them before the injury. The KAS-R1 asks for a retrospective assessment of the patient's pre-morbid behaviour and, on the same scale, for a current rating. It is therefore quite possible that one rating may affect the other. In addition, through the stress of the situation, or even to reflect themselves in a more favourable light, the relative may subconsciously have formed an idealistic view of the patient, and be unwilling or unable to recall the patient's failings prior to the injury. This will result in the patient appearing more affected by the injury than is in fact true.

One possible solution to the problem of pre-morbid assessment would be to use normative data where available. For example in the UK, normative data is available for the SF-36 and this may be broken down by factors such as age group or social class and therefore tailored to the particular population of interest.

8.6 METHOD OF DATA COLLECTION

This thesis has used both face-to-face interviews and a postal survey to collect data. Although the interview study achieved a higher response rate and more complete data than the postal survey, this method is expensive in terms of resources and may not be practical in some circumstances. The postal survey method did not appear suited to an older population of TBI subjects as judged by the relatively low completion rates of the SF-36 by this group. Possibly older people felt that the questions in the SF-36 were unacceptable or irrelevant to them rather than reflecting their lack of co-operation in this method of data collection. Further study into this is indicated. The other issue is that over half the interview sample and almost one in six of the postal sample required assistance from others to fill in the questionnaire. This must be taken into account in interpreting such results as it is known that subject and proxy views may differ (Epstein et al. 1989; Spatt et al. 1997).

8.7 SEVERITY OF TRAUMATIC BRAIN INJURY

It is interesting that there were only minimal differences found between the mild, moderate and severely injured patients. It is generally assumed that mildly injured patients will have very few, if any, on-going problems. Dikmen and Levin (1993) studied a group of mild TBI patients one to three months post-injury, and found that they had only selective and subtle neuropsychological problems. Kibby (1996) found that cognitive deficits following mild TBI normally resolved after six months and that chronic disability or permanent cognitive impairment was rare. However, the natural history of subjective complaints is less certain and although there is consistency amongst the early symptoms, there is great variation in the number and combination reported (Dikmen and Levin, 1993). Bohnen et al. (1994) conducted a postal survey of late post-concussional symptoms at 1-5 years after mild TBI, and concluded that the symptoms experienced in the mildly injured were the same as those in the control population, but at a greater frequency.

There are no reliable estimates of late symptoms in mildly injured patients because of differences in case selection and symptom evaluation, and there are several problems when studying this group (Dikmen and Levin, 1993). Firstly, the accurate assessment of severity may be difficult as PTA may only be short and retrospective assessment may be imprecise; the upper end of the GCS is thought to be less sensitive and may be affected by alcohol consumption; and the definition of TBI is often vaguely defined and therefore patients with

only minimal or no neurological damage may be diagnosed as having a TBI (Kibby and Long, 1996). The classification of TBIs in to mild, moderate and severe categories was done somewhat arbitrarily (Rimel et al. 1981; Rimel et al. 1982) and this may lead to difficulties in making comparisons between severity groups. In order to explore outcome, some studies combine mild and moderate TBIs and compare this group with the severely injured, rather than using the three severity categories. Secondly, CT scanning is often not undertaken in the mildly injured and therefore intracranial lesions may be missed (Williams et al. 1990). Finally, the majority of studies focus on patients admitted to hospital and as such are not representative of the mildly injured population as a whole. This last point is particularly relevant to the current study as all patients had been admitted to hospital. Therefore, this sample is likely to represent the more severe end of the mildly injured patients, and it would be reasonable to expect that they might have a higher frequency of problems than the rest of this group.

Although the majority of mild TBI patients recover fully, a very small proportion continue to have ongoing difficulties. However as there are very large numbers of mild TBIs, the actual numbers affected is considerable. As previously mentioned it would be useful to be able to predict which patients might be at higher risk of having ongoing problems.

8.8 WHEN TO ASSESS OUTCOME

This thesis has found that no difference in outcome was evident relating to time post-injury. This raises the issue of when and how often patients should be assessed. It is generally accepted that most recovery takes place in the early stages after injury and follows a negatively accelerating curve, which gradually reaches a limit (Newcombe, 1982). It was originally believed that little if any recovery took place after the first twelve months, although it is now recognised that improvement may continue for some years (Thomsen, 1984; Oddy et al. 1985; Brooks et al. 1987; Rappaport et al. 1989; Vogenthaler et al. 1989). However, it is very difficult to determine when recovery can be regarded as complete as the pattern depends on the nature and complexity of the functions being examined and will vary between individuals (Richardson, 1990a; Rimel et al. 1990). Hence, it is very difficult to predict the pattern, time course and ultimate extent of recovery in a given individual (Brooks and Aughton, 1979). This study found that no differences were evident over the period of follow up (5-12 years). This may relate to the particular outcome measures used which may have been insensitive to differences between patients. Or, it might be that recovery had stabilised in the first few years after injury although clinically significant

improvements may still occur. It is therefore suggested that frequent assessment at this stage after TBI is not a worthwhile exercise but further research into the early years after injury would help clarify the type and extent of improvement that an individual might expect.

8.9 SUMMARY

This thesis has attempted to assess the utility of a recently developed outcome measure and to describe the long term outcome following TBI. It has found that there is currently no single measure which can adequately describe the consequences of this insult but that several different measures may be required. This reflects the broad range of sequelae which may follow a TBI. Although the aim of the EHIEC was to provide a measure which would address the many different areas affected by this type of injury, even this supposedly comprehensive measure suggests that further more detailed assessment may be required for some aspects. For example, the FIM is recommended for a more detailed analysis of ADL. As this illustrates, it may in fact be more advantageous to use a variety of well known, psychometrically sound measures rather than attempting to develop a new all-inclusive scale. That being said, many of the current measures have problems such as poor validity or reliability. There is therefore a need to continue to determine the psychometric properties and utility of the current outcome measures and to design robust measures specifically to address handicap many years after TBI.

This research would therefore suggest that statistically significant improvement is unlikely in a mixed severity TBI population more than five years post-injury. Much of the current research in this population has been focused on the first two years after injury. It is vital to establish the degree of improvement, or deterioration, between years two and five as this will provide a guide for clinicians and service providers. It is also important to determine the optimal time interval between assessments. Given that the rate of change at this stage after injury is likely to be slow, annual assessment may be appropriate as the benefit gained from frequent examination must be weighed against the costs. Which measure(s) should be used must be guided by the aims of assessment. This research has suggested that the SF-36, particularly in interview format, and the CIQ may be an appropriate measures to use as part of an assessment package. The SF-12, an abbreviated version of the SF-36, may prove to be superior but requires further research.

This thesis has added to the pool of knowledge about the long term outcome of TBI by studying relatively large numbers of this population. Whilst it has been unable to recommend a single, multidimensional measure which is ideal for the assessment of this population, it has further explored some disease specific and generic measures and has highlighted their relative strengths and weaknesses. It has also studied interview and postal methods of data collection and reported on their use in this sample. This study has found that long term outcome appears similar between the mild, moderate and severely injured patients and whilst this may reflect the true situation, it may also relate to the lack of sensitive or appropriate measures available.

> 'A carpenter's best tool may sometimes be a hammer. But many constituencies would say that a hammer is all we have currently. We need more refined tools at our disposal. Only then do we have the option to decide whether a hammer or a more sophisticated tool is the most appropriate for the task'
>
> (Frattali, 1993)

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Appendix A

The European Head Injury Evaluation Chart

EVALUATION
OF
TRAUMATIC BRAIN INJURY

E.B.I.S. DOCUMENT

EUROPEAN BRAIN INJURY SOCIETY

E. B. I. S.

D.N. BROOKS and J-L TRUELLE

with the collaboration of an E.B.I.S. working group
and the help of a grant from the Directorate General
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(INSTITUT DE RECHERCHE INTERNATIONAL SERVIER)

HEAD INJURY EVALUATION CHART
E.B.I.S. DOCUMENT
FIRST PART

PRELIMINARY INTERVIEW

Explain the purposes and method of this evaluation (as described on the previous sheet).
Then ask the head injured person (and/or accompanying person) to explain in their own words their history, their **problems, and needs**.
Write the main points resulting from this introductory examination.

HISTORY

SPONTANEOUS COMPLAINTS AND NEEDS REPORTED BY THE PATIENT

INFORMANT'S OPINION

1. INITIAL INFORMATION

This part (items 1-52) is to be completed at initial examination, during the first hospitalisation if possible. Otherwise this first evaluation may be completed afterwards from the history and early medical and other records. The examiner is encouraged to ***write his/her own comments****, on the right side of the chart, between the scoring and the coded answers. Missing information (or inappropriate item) is always coded as 9, 99, 999 etc.*

Name of examiner (or stamp)

Address and telephone

Qualification

Service/department

1.1 PATIENT IDENTIFICATION

RECORD 1

01 **Patient indentification code** ..... I__I__I__I__I__I__I__I__I 01-08
Use the international phone code
for the country (see appendix 3)

02 **Date of birth** (dd/mm/yy) ..... I__I__I__I__I__I__I 09-14

03 **Age at examination** ..... I__I__I 15-16

04 **Date of examination** (dd/mm/yy) ..... I__I__I__I__I__I__I 17-22

05 **Date of accident** (dd/mm/yy) ..... I__I__I__I__I__I__I 23-28

06 **Sex :** ..... I__I 29
Male 0
Female 1

07 **Marital status** ..... I__I 30
Single 0
Widow 1
Married 2
Cohabiting 3
Divorced/separated 4

08 **Home :** ..... I__I 31
Where did the patient sleep for the few nights before the accident?
His home 0
Parents' home 1
Spouse's home (if different
from personal home) 2
Centre or therapeutic home 3
Hospital 4
Other 5
Specify _____

09 **How many years of normal education?** ..... I__I__I 32-33
(including school, college, university)
You may include qualitative information specific to your own country.

10 **Occupation before accident** ..... I__I 34

Housewives are to be coded according to occupation before marriage.
Students, school children coded by father's occupation.
As for item 9, you may add qualitative information specific to your own country and precise the patient's professional activity.

- Professional, Executive, Manager..... 0
- Intermediate; head clerk; businessman; large scale farmer..... 1
- Skilled occupations; small farmer office worker, foreman, shopkeeper ... 2
- Semi-skilled occupations, lower office workers..... 3
- Unskilled occupations 4
- Student or still at school..... 5
- Other 6
- Specify _____

11 **Occupational status at the time of accident** ..... I__I 35

Full time working..... 0
Part time working 1
Retired..... 2
Unemployed worker 3
Unemployed (ill) 4
Housewife 5
Child-preschool..... 6
Child-at school/student 7
Other 8
Specify _____

1.2 PRE-TRAUMATIC SITUATION

In your clinical judgement, is there pre-traumatic evidence of major disabling conditions/problems, with **significant functional consequences?** For each item, indicate the kind of problem to the left of the coding box. Exceptions are indicated for specific items. Otherwise, code as follows: No = 0 and Yes = 1.

12 **Informant** ..... I__I 36

The patient himself..... 0
Spouse..... 1
Parent 2
Friend 3
Tutor 4
Patient and other informant..... 5
Other 6
Specify _____

13 **Surgical/Medical Problems treated in hospital** ..... I__I 37

14 **Previous Head Injury with Sequelae** ..... I__I 38

15 **Psychiatric Problems treated by specialist or hospitalisation** ..... I__I 39

16 **Epilepsy** ..... I__I 40

17 **Addiction** (alcohol/drugs) ..... I__I 41

18 **Pre-Existing Physical or Sensory Disability** ..... I__I 42

19 **Pre-Existing Mental Disability** ..... I__I 43

20 **Family Problems** (eg separation or divorce of patient or parents) ..... I__I 44

21 **Social Problems** (eg referred to social work or police) ..... I__I 45

22 **Vocational or educational problems** ..... I__I 46
(fired from work, frequent or prolonged unemployment)
(more than one reduplication or special education)

POSITIVE ASPECTS

The examiner is requested to investigate positive aspects and strengths of the pretraumatic situation (educational, occupational, leisure sport). Indicate achievements, successes, or positions of responsibility which may form a basis for rehabilitation.

1.3 CIRCUMSTANCES OF ACCIDENT

23 **Type of accident** ..... I__I 47
Road traffic accident :
- Driver (car or truck) 0
- Passenger (car or truck) 1
- Pedestrian 2

Other road traffic accident:
- motorbike 3
- bicycle 4

Sport/recreation 5
Domestic 6
Assault (including military) 7
Other 8
Specify _____

24 **Work accident** ..... I__I 48
No 0
On the way to/from work 1
At work 2

25 **Other serious or fatal victims in accident** ..... I__I 49
Neither relative nor friend hurt 0
Relative or friend hurt 1
Relative or friend killed 2
Other serious victim 3
Other fatal victim 4
Combination 5
Specify _____

1.4 SEVERITY OF INJURY

This section must be completed by a physician or through medical records.

1.4.1 ALTERED CONSCIOUSNESS

The Glasgow Coma Scale		
1. Eye opening	**2. Motor response**	**3. Verbal response**
none.....1	no response 1	no response.....1
to pain.....2	extension 2	incomprehensible.....2
to speech.....3	abnormal flexion 3	inappropriate.....3
spontaneous 4	withdrawal.....4	confused 4
	localized pain.....5	oriented.....5
	obeys commands.....6	

26 **Glasgow coma score** .....I__I__I 50-51
Record worst score on Glasgow Coma Scale (CGS)
during the first 24 hours (minimum: 3 - maximum: 15)

27 **Coma length** .....I__I__I__I 52-54
Days **to obey simple commands** (not only eye opening)

28 **Post Traumatic Amnesia** .....I__I 55
(interval from injury to regaining continuous day-to-day memory).
This may be assessed retrospectively
0 to 1 hour.....0
1 hour to 1 day 1
1 to 7 days.....2
8 to 28 days.....3
29 to 60 days 4
More than 60 days 5

OPTION A scientific study of PTA demands a scale such as the G.O.A.T. (LEVIN H.S. et al. The Galveston Orientation and Amnesia Test. Journal of Nervous and Mental Diseases. 1979. 167. 675-684 - Address : Neurosurgery University Center. Baltimore. Maryland 21201-1595. U.S.A.).

Include here the summary or the conclusion of the neuroimaging report(s) (C.T., M.R.I.)...

1.4.2 INITIAL MANAGEMENT

29 **Tracheostomy** .....I__I 56
No.....0
Yes.....1

30 **Assisted ventilation** ..... I__I 57
No 0
Yes 1

31 **Early sedation** ..... I__I 58
No 0
< 24 hours 1
1-7 days 2
> 7 days 3

32 **Did consciousness ever deteriorate from initial level?** ..... I__I 59
(effects of sedation excluded)
No 1
Yes 0

Injuries to the Head

33 **Basal fracture** ..... I__I 60
No 0
Yes 1

34 **Other fracture** ..... I__I 61
None 0
Linear 1
Depressed 2
Linear and depressed 3
Other 4
Specify _____

Injuries to the Brain

35 **Penetrating injuries** ..... I__I 62
None 0
Visible dura 1
Visible brain 2

36 **Haematoma (excluding haemorragic contusion)** ..... I__I 63
None 0
Extra-dural 1
Sub-dural 2
Intra-cerebral 3
Combination 4
Specify _____

37 **Other lesions (not haematoma)** ..... I__I 64
None 0
Focal haemorrhagic contusion 1
Diffuse haemorrhagic contusion 2
Other focal lesion 3
Other diffuse lesion
(axonal diffuse lesions identified
on neuroimaging, CT or MRI) 4
Combination 5
Specify _____

38 **Site of major damage (Haematoma or other)** ..... I__I 65
- No lesion identified on neuroimaging 0
- Right frontal 1
- Left frontal 2
- Bilateral frontal 3
- Right posterior hemispheric 4
- Left posterior hemispheric 5
- Posterior fossa 6
- Peri-ventricular 7
- Diffuse 8

39 **Neurosurgical intervention (exclude ICP monitoring)** ..... I__I 66
- None 0
- Haematoma 1
- Other 2
- Specify _____

Extra-Cranial Complications

40 **Cardiovascular** ..... I__I 67
- None 0
- Shock or cardiac arrest 1
- Thrombo-embolism (except pulmonary) .2
- Combination 3
- Other 4
- Specify _____

41 **Pulmonary** ..... I__I 68
- None 0
- Haemo-or pneumothorax 1
- Pulmonary embolism 2
- Infection 3
- Combination 4
- Other 5
- Specify _____

42 **Infection (not pulmonary)** ..... I__I 69
- None 0
- Urinary 1
- Oro-facial 2
- Septicemia 3
- Combination 4
- Other 5
- Specify _____

Extra-cranial Injuries (describe the lesions) RECORD 2

43 **Thorax (exclude simple fracture of ribs)** ..... I__I 70
- No 0
- Yes 1

44 **Abdomen** ..... I__I 71
- No 0
- Yes 1

45 **Pelvis** ..... I__I 72
- No 0
- Without urinary tract lesion 1
- With urinary tract lesion 2

46 **Spine** ..... I__I 73
- None 0
- Lesion with no neurological complication 1
- Neurological complication 2

47 **Right upper limb** ..... I__I 74
- None 0
- Bone 1
- Joint 2
- Cutaneo-muscular 3
- Combination 4

48 **Left upper limb** (code as item 47) ..... I__I 75

49 **Right lower limb** (code as item 47) ..... I__I 76

50 **Left lower limb** (code as item 47) ..... I__I 77

51 **Injuries to face and jaw** ..... I__I 78
- None 0
- Teeth 1
- Jaw 2
- Other facial bones 3
- Joints 4
- Cutaneo-muscular 5
- Combination 6
- Specify _____

52 **Burns requiring investigation or intervention** ..... I__I 79
- No 0
- Yes 1

OPTION For a more detailed study on the severity of injury, ISS can be used (BAKER S.P., O'NEILL B. HADDON W. LONG WB. The Injury Severity Score : a method of describing patients with multiple injuries and evaluating emergency care. J. Trauma 1974; 14:187-197).
For more detailed initial information, you can use the Canadian document "Histoire et Examen des Traumatisés Crânio-encéphaliques", version neurochirurgicale abrégée. PROVOST J., BOULANGER Y.L., 1993. Address: Institut de Réadaptation de Montreal, 6300, avenue Darlington, Montréal, Québec, CANADA.

Attention ! The examiner must list the precise cranial and extra-cranial lesions here in a way which would allow the preparation of a medical certificate

HEAD INJURY EVALUATION CHART
E.B.I.S. DOCUMENT
SECOND PART

2. FOLLOW UP

A new copy of this and all subsequent pages should normally be completed at each evaluation. Suggested schedule: First hospitalisation, then 3 months +/- 15 days ; 6 months +/- 1 month ; 1 year +/- 1 month ; within the 3rd year ; within the fifth year.
At first examination, this second part must be filled in as completely as possible. For more severe injuries only a partial completion may be possible.
The participation of a relative is crucial (if possible the person responsible for the care of the patient).
Do not forget that missing or inappropriate information is always coded 9,99,999 etc.

If the examiner or relative is different from that on the first examination, please indicate here.

Name

Qualification

Service/department

Adress and telephone

RECORD 2

53 **Follow up:** ..... I__I 01
First examination 1
Second examination 2
Third examination 3
and so on . . .

54 **Patient identification code** ..... I__I__I__I__I__I__I__I__I__I 02-09

55 **Date** (dd/mm/yy) ..... I__I__I__I__I__I__I__I 10-15

2.1 COMPLAINTS

Without prompting, ask the patient to describe the problems he/she finds in daily life. Also interview a relative (alone if necessary) on patient's problems.

PATIENT:
RELATIVE:

2.2 CURRENT SITUATION

This section should be filled in during the first hospitalisation and at each stage of follow-up.

2.2.1 CURRENT LIVING (at the time of examination)

56 **Current daily activity** ..... I__I 16

- Work/school 0
- Vocational training programme 1
- Rehabilitation service 2
- Hospital (not rehabilitation) 3
- Psychiatric centre 4
- At home - no activity 5
- Day center 6
- Long-term institution care 7
- Other situation 8

Specify _____

57 **Where does the patient usually sleep at night?** ..... I__I 17

- Own accomodation 0
- Family home 1
- Supported living 2
- Institutional living 3
- Other 4

Specify _____

58 **Length of stay in acute care (days)** ..... I__I__I__I__I 18-21
(excluding rehabilitation)

59 **Number of days in residential rehabilitation centre(s)** ..... I__I__I__I__I 22-25

60 **Number of days in out-patient centres** ..... I__I__I__I__I 26-29
e.g. transitional vocational or occupational centres

List here, with their addresses, all the departments and centres which have been used by the patient (including initial care, rehabilitation and re-entry facilities):

2.2.2 COMPLICATIONS

Neurological

61 **Post-traumatic epilepsy** ..... I__I 30

- No 0
- Generalised 1
- Focal 2
- Combination 3

62 **Fit frequency** ..... I__I 31
None 0
1 fit only during the first week 1
1 fit only after the first week 2
More than 1 fit after the first week 3

63 **Meningitis or meningo-encephalitis** ..... I__I 32
No 0
Yes without sequelae 1
Yes with sequelae 2
Specify _____

64 **Hydrocephalus** ..... I__I 33
None 0
Yes, successfully treated 1
Other 2
Specify _____

65 **Chronic subdural haematoma** ..... I__I 34
None 0
Successfully treated 1
Other 2
Specify _____

66 **Urinary** ..... I__I 35
None 0
Infection 1
Other 2
Specify _____

67 **Cutaneous** ..... I__I 36
None 0
Residual scar only 1
Sores needing nursing care 2
Sores needing surgery 3
Combination 4
Specify site/s _____

_____

68 **Other complications** ..... I__I 37
No 0
Yes 1
Specify: (eg tracheal, _____
endocrine, other neurological
or orthopaedic complications) _____

2.2.3 CURRENT TREATMENT (resulting from the accident)

Exceptions are indicated for specific items. Otherwise, code as follows: No = 0 and Yes = 1.

Current medication

69 **Anticonvulsants** ..... I__I 38

70 **Major Tranquillisers** (neuroleptics) ..... I__I 39

71 **Benzodiazepines or other tranquillisers/ hypnotics** ..... I__I 40

72 **Antidepressants** ..... I__I 41

73 **Analgesics** ..... I__I 42

74 **Others (antispastic medication. etc...)** ..... I__I 43
Specify: _____

Current Clinical Management (during the 3 months up to the examination)

75 **Physical therapy** ..... I__I 44

76 **Occupational therapy** ..... I__I 45

77 **Speech therapy and/or other cognitive therapy** ..... I__I 46

78 **Psychiatry/Psychology** ..... I__I 47

79 **Rehabilitation physician** ..... I__I 48

80 **Social work and/or vocational specialist** ..... I__I 49

81 **Other therapy** ..... I__I 50
Specify: _____

82 **Surgical treatment** ..... I__I 51
If first examination, specify any surgery which has resulted from the injury.
If second or later examination, identify surgical operations since last evaluation.
None.....0
Neurosurgery.....1
Orthopaedic.....2
Plastic.....3
Other.....4
Combination.....5
Specify kinds and dates: _____

_____

_____

2.3 IMPAIRMENTS, DISABILITIES (Following the WHO classification)

In this part most items reflect impairments, but scoring of severity of disturbances has deliberately been based on disabilities criteria. This is done in order to plan clinical management.

Base your assessment firstly on the presentation of the patient during your examination: then on the information supplied by the person accompanying the patient and the patient. If these do not correspond, your clinical judgement will need to be exercised.

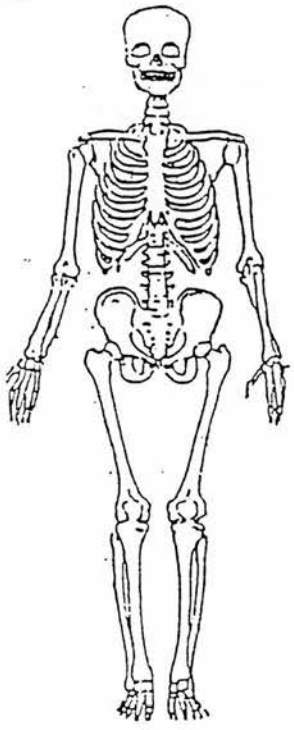
The severity of disability is in terms of functional (handicapping) consequences.

The scoring is (exceptions are indicated) :

0 = No impairment, no disability

1 = Mild moderate : means that independent daily function is still possible in basic activities of daily living (see p. 20)

2 = Severe : prevents such independance in at least one of those activities



83 Handedness ..... I__I 01
Right 0
Left 1
Ambidextrous 2

Motor impairments leading to a disturbance of function

Orthopaedic

84 Reduced amplitude in movements of any limb joint .... I__I 02
None 0
Mild/Moderate in one limb only 1
Severe in one limb only 2
Mild/Moderate in more than 1 limb 3
Severe in more than 1 limb 4
Other 5
Specify _____

Please indicate on the skeleton the functionally impaired joints. For a more precise (eg medico-legal) evaluation use a goniometer to record residual amplitudes of the impaired joints.

85 Cause of orthopaedic impairment ..... I__I 03
None 0
Osteoma(s) 1
Fixed contractures 2
Complications of initial fractures
(osteonecrosis, infection...) 3
Other 4
Specify _____
Combination 5
Specify _____

Neurological

86 Hemiparesis (with or without spasticity) ..... I__I 04
None 0
Right : Mild/Moderate 1
Left : Mild/Moderate 2
Right : Severe 3
Left : Severe 4
Mild double hemiparesis 5
Severe on 1 side 6
Severe on 2 sides 7
Other central paralysis (paraparesis, tetraparesis...) 8
Specify _____

87 Spasticity ..... I__I 05
None 0
Mild unilateral disturbance
of upper and/or lower limb use 1
Severe unilateral disturbance 2
Mild disturbance of all limbs 3
Severe disturbance of all limbs 4
Other 5
Specify _____

88 **Peripheral Paralysis** (excluding cranial nerves) ..... I__I 06

None....0
Mild/Moderate right brachial plexus....1
Mild/Moderate left brachial plexus....2
Severe right brachial plexus....3
Severe left brachial plexus....4
Moderate other peripheral paralysis (eg external sciatic popliteal)....5
Severe other peripheral paralysis....6
Specify _____
Any combination....7
Specify _____

89 **Cerebellar syndrome, dyskinesia, tremor,** ..... I__I 07
dystonia or other problems of coordination

Same coding as for item 84 (spasticity)

Describe the problems :

90 **Gait disturbances** ..... I__I 08

None....0
Slight problems with balance
but not identified in examination....1
Slight problems with balance demonstrated clinically
but allowing daily independent activity....2
Mild gait disturbances with some impairement of daily activity....3
Severe gait disturbances preventing independant daily activity....4

91 **Visual acuity problems** ..... I__I 09

None....0
Right : Mild/Moderate (Visual acuity >3/10)....1
Left : Mild/Moderate....2
Right : severe (visual acuity ≤3/10)....3
Left : severe....4
Bilateral moderate disturbances....5
Bilateral severe disturbances....6
Combination....7
Specify _____

92 **Visual field deficit** ..... I__I 10

None....0
Mild/Moderate....1
Severe....2
Specify _____

93 **Oculo-motor deficit** ..... I__I 11

Same coding as for item 92 (Visual field deficit)
Specify nerves and treatments: _____

_____

94 **Auditory deficit** ..... I__I 12
Same coding as for item 92 (Visual field deficit)

OPTION If there is any visual or auditory deficit, a specialized ophthalmic/ENT examination (including an audiogramme) is necessary. Remember the patient is not always a good judge and is often unaware of his own disabilities which may be complicated and handicapping.

95 **Olfactory and/or gustatory deficit** ..... I__I 13
Same coding as for item 92 (Visual field deficit)

96 **Impairment of other cranial nerves** ..... I__I 14
Same coding as for item 92 (Visual field deficit)
Specify the nerve(s) (V, VII, VIII vestib., IX, X, XI, XII) : _____

_____

_____

97 **Chronic pain** ..... I__I 15
Same coding as for item 92 (Visual field deficit)
Specify location of pain(s) : _____

_____

_____

2.3.2COGNITIVE STATUS

Exceptions are indicated for specific items. Otherwise, code as follows:
0 = None.
1 = Mild/Moderate : reported by the patient or informant during the last month but not observed by the examiner.
2 = Severe : observed by the examiner or other clinician.
In testing, record the first answer.

98 **Attention** ..... I__I 16
Does the patient show any of the following problems :
Difficulty in maintaining attention, mental fatigue during the examination,
or inability to follow a conversation involving more than two persons?
None 0
Mild/Moderate 1
Severe 2

99 **Mental control** ..... I__I 17
Ask the patient to perform "serial 7's" from 100 down to 72.
(100, 93, 86, 79, 72). Record number of errors (Max. 4).

Communication

100 **Is speech comprehensible?** ..... I__I 18
Yes 0
Mild dysarthria, dysphonia 1
Severe dysarthria, dysphonia 2
Mild aphasia allowing usual speech 3
Severe aphasia preventing usual speech 4
Combination 5
Specify _____

101 **Oral understanding** ..... I__I 19
Does he/she have difficulty (aphasic) in understanding what is said to him/her?

102 **Verbal fluency** ..... I__I 20
Ask patient to produce the names of as many animals as possible in 60 seconds.
Record number produced. Normal score for healthy persons : 18±4 (SD) (Goodglass).

103 **Reading** ..... I__I 21
Ask the patient to read aloud the following lines:
"There was a fire in a large London department store in Oxford Street. The manageress, Mrs.Smith thought that it was a cigarette which had not been put out, which caused the fire in the basement".
Score as follows:
No problem 0
Mild/Moderate (eg occasional ommission
or paralexia but understanding not impaired) 1
Severe (at least one sentence unintelligible) 2

104 **Writing** ..... I__I 22
Ask the patient to write a sentence of his/her own below

_____

No problem 0
Mild motor problem 1
Severe motor problem (unreadable writing) 2
Mild/Moderate impairment of spelling or syntax 3
Severe impairment of spelling or syntax 4
Combination 5
Specify _____

Orientation, Memory and Learning

If post-traumatic amnesia has not been already assessed, specify on item 28.

105 **Does he/she get lost?** ..... I__I 23
No 0
In unfamiliar places 1
In familiar places 2

106 **Spatial/temporal orientation** ..... I__I 24
Can he/she give the exact date, and the name of the place of examination
(name of hospital or centre)?
No problem (on the date a 2 day error is allowed) 0
Mild/Moderate problem (1 item incorrect) 1
Severe problem 2

Memory and learning

Present verbally (1 word per second) the following words for learning. Say to the patient: "I am going to give you 10 words to remember. As soon as I finish, give me as many words as you can, in any order." Repeat twice with the same instruction. Indicate, under each word, the order in which it was recalled (1,2,3 etc.). Record, in boxes, the correct number on each of the 3 attempts.

Rose Night Car Paper Snow Dog Bottle Eye Watch Chair

107 I ..... I__I__I 25-26

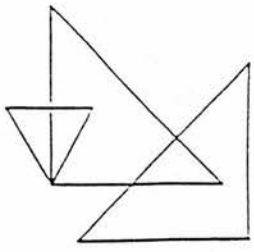
108 II ..... I__I__I 27-28

109 III ..... I__I__I 29-30

Specify extra items : _____

110 **Perception, Construction** ..... I__I 31
Can the patient copy these three triangles?

MODEL COPY



1 mark for each triangle - 1 mark for proper placement of the small triangle
2 marks for correct intersection of the 2 larger triangles
Score from 0 to 6 - Normal scoring: 6

Logical Reasoning

111 **Peter has 4 apples, John has 3 more than Peter. How many have they all together?** . I__I 32
Correct 0
Incorrect 1

112 **How are a boat and a car alike?** ..... I__I 33
Correct 0
Incorrect 1

OPTION If any cognitive disturbances have been identified in this short screen, please refer the patient for further specialised examination, eg neuropsychology, speech and language, preferably to a specialist skilled in traumatic brain injury.

Mental Functioning, Judgment

For coding, refer to cognitive status: 0 = None, 1 = Mild/Moderate, 2 = Severe

113 **Form of thinking** ..... I__I 34
Does he/she show rapid shifts in ideas, or deficient filtering of irrelevant ideas?

114 **Loss of self-criticism** ..... I__I 35
Does he/she understand that something he/she says or does upsets someone else?

115 **Denial, anosognosia** ..... I__I 36
Does he/she deny or minimise his/her physical, cognitive or behavioural problems?

116 **Executive Functions** ..... I__I 37
Is the patient able to carry out a simple sequential task eg making coffee or a simple meal?

2.3.3 AFFECTIVE AND BEHAVIOURAL STATE RECORD 4

This section should be completed at 3 months or later after injury. The questions are designed to identify some of the most common emotional/behavioural changes, and levels of stress in the patient.

Problems are only scored as present if they have appeared or increased since the injury.

Exceptions are indicated for specific items. Otherwise, code as follows:
0 = None
*1 = Reported by the informant, regarding the past month **(patient's opinion is excluded in this section)***
2 = Observed by the examiner

For each item, score if any of the problems is present.

117 **Loss of emotional self-control** ..... I__I 01
Is he/she verbally aggressive, or showing anger over trivial annoyances or without reason, or failing to control his/her temper when something upsets him/her?

118 **Mental excitement, talkativeness** ..... I__I 02
Does he/she talk rapidly and excessively without making much sense?

119 **Lack of personal hygiene** ..... I__I 03
Is he/she dirty, ill-groomed, careless of dress?

120 **Avolitional, aspontaneous** ..... I__I 04
Does he/she lack initiative or motivation?
Does he/she show diminished emotion?
Does he/she stand or sit for long periods without doing anything?

121 **Depression** ..... I__I 05
Does he/she express sadness, gloominess, pessimistic ideas, a feeling of hopelessness or total incapacity, a loss of self-esteem?

122 **Anxiety** ..... I__I 06
Does he/she show anxiety or overconcern?

123 **Sexual behaviour** ..... I__I 07
Has the patient shown any change in sexual interest (libido) as compared with before the accident?
- No change 0
- Mild/Moderate disinhibition 1
- Severe disinhibition 2
- Mild/Moderate reduction in sexual interest 3
- Severe reduction 4

124 **Patient's grief and "mourning", rebuilding of a new identity** ..... I__I 08
Does the patient accept he/she is not the same since the accident or, on the contrary, does the patient have difficulties in accepting his/her current situation and still hopes for a complete return to his/her previous state?
The examiner has to evaluate the patient's "mourning":
- Satisfactory acceptance 0
- Insufficient acceptance 1
- No acceptance 2

125 **Informant's mourning** ..... I__I 09
Now the examiner has to evaluate the informant's "mourning":
Does the informant accept the patient is no longer the same?
Score as for the previous item *(To be filled in with a family member only)*

126 **Patient's motivation** ..... I__I 10
Has the patient been enthusiastically engaged in his/her rehabilitation over the past 3 months? Give example(s) :

_____

_____

_____

The examiner has to evaluate the patient's engagement:
- Clearly engaged 0
- Mild/moderate engaged 1
- No engagement 2

127 **Informant's motivation** ..... I__I 11

Is the accompanying person actively engaged in promoting the patient's rehabilitation over the past 3 months? Give example(s) :

_____

_____

The examiner has to evaluate the informant's engagement.
(Score as for the prievious item)

128 **Verbal memory recall** ..... I__I__I 12-13

Ask the patient to recall the ten words previously learned (item 104)
(Normal score: a minimum of 5 words)

129 **Visuo-spatial memory recall** ..... I__I 14

Ask the patient to draw from memory the 3 triangles previously copied:

DRAW FROM MEMORY

Score as item 107 - Enter score in box (A normal score is 6)

130 **Subjective Distress of the patient** ..... I__I 15

Now ask the patient in the absence of the informant to use the line below to rate, from 0 to 6, the distress resulting from the injury and its consequences.
Enter score (0-6) in box.

6 5 4 3 2 1 0
I_____I_____I
Severe stress Moderate stress No stress

2.4 SYNTHESIS TO BE COMPLETED BY THE EXAMINER:

Considering **the physical, intellectual and behavioural impairments and disabilities** of the patient, what in your judgement are **the most serious problems identified?**

You are requested to express, as far as possible, these problems in terms of anatomic or aetiological diagnosis (frontal syndrome for instance) and to identify the 3 main problems (but without ignoring others).

1. _____

2. _____

3. _____

Others _____

OPTION If any behavioural disturbances have been identified in this short screen, please refer the patient for further specialised examination and, more particularly, use the H. LEVIN Neurobehavioural Rating Scale, Journal of Neurology, Neurosurgery and Psychiatry, 1987, 50, 183-193 - Address : Neurosurgery University Center, Baltimore, Maryland 21201-1595 U.S.A..

2.5 DISABILITY AND HANDICAP

Attention! *This section should be completed when planning discharge from hospital rehabilitation centre, or at a later date. It is designed to help the interviewer* ***identify the services which will be needed in the community.*** *It also suggests ideas for using existing resources in flexible and imaginative ways.*

The assessment should be based both on data from the examination, and from the informant's opinion concerning the 3 last months. If these do not correspond, the interviewer must exercise his/her clinical judgement.

Exceptions are indicated for specific items. Otherwise, code as follows:
0 = Normal, independant
1 = Independant but some diminution (eg slowness or need for technical help)
2 = Partly independant (needs human help or stimulation some of the time)
3 = Severe dependance (needs human help or stimulation most of the time)
For each item, score if any of the problems is present.

2.5.1 ACTIVITIES OF DAILY LIFE

The aim here is to assess physical and mental aspects of independance.

Basic activities of daily life RECORD 5

131 Eating, drinking ..... I__I 01

132 Sphincter control ..... I__I 02
Score 1 for : increased frequency of urination, or "dribbling"

133 Toileting ..... I__I 03

134 Dressing ..... I__I 04

135 Transfers ..... I__I 05
(getting up, going to bed, going from the bed to the arm chair)

136 Mobility at home ..... I__I 06

Advanced activities of daily life

137 Mobility outside the home ..... I__I 07

138 Going out shopping ..... I__I 08

139 Using public transport ..... I__I 09

140 Driving a car ..... I__I 10

141 Writing a letter ..... I__I 11

142 Financial management and administrative tasks ..... I__I 12

OPTION For clinical and/or medico-legal purposes, it can be useful to have the patient list, with the help of relatives, his routine activities (toileting, meals, sleep, rehabilitation) or unusual activities (going out, travelling) with times and duration for a sequential seven day period.
Severe handicap, particularly physical, may justify the use of further investigation e.g. via the FIM (Functional Independance Measurement) GRANGER C.V. Functional Assessment in Rehabilitation Medicine, Williams & Wilkins ed., Baltimore, 1984, 14-25.

Third person

143 **Does the patient need help from a third person for physical reasons?** ..... I__I 13
No 0
Occasional 1
Continual 2

144 **Does the patient need help from a third person for cognitive or behavioural reasons?** ..... I__I 14
Score as item 140

145 **Legal guardian** ..... I__I 15
Not necessary 0
Necessary but not done 1
In process 2
Achieved 3

Specify the kind of protection and the appointed person : _____

_____

2.5.2 FAMILY, RELATIVES, AND ACCOMODATION

Because of the injury and consequences . . .

146 **Have any family member had to seek help for himself or taken medication because of stress?** ..... I__I 16
No 0
Yes 1

147 **Has the family incured additional expenses?** ..... I__I 17
No 0
Yes 1

148 **Has any family member had to give up or modify work or education to care for the patient?** ..... I__I 18
No 0
Yes 1

149 **Have there been any significant changes in family roles?** ..... I__I 19
(Ex: spouse becoming the head of the family - unlike before accident)
No 0
Yes 1
Specify _____

150 **Have there been any behaviour problems in uninjured children in the family?** ..... I__I 20
No 0
Yes 1

151 **Does the family feel a need for the patient to have partial or permanent respite care?** ..... I__I 21
No 0
Yes 1

152 **Assess "significant other"s behaviour** ..... I__I 22
Appropriate 0
Over protective 1
Distant 2
Aggressive 3
Other/combination 4
Specify _____

153 **Informant's subjective distress** ..... I__I 23

Now ask the informant: "How much stress have you felt under since the injury?"
Please, score this distress from 0 to 6 using the line below.
Enter score (0-6) in box.

6 5 4 3 2 1 0
I_____I_____I
Severe stress Moderate stress No stress

154 **Is there need for structural changes in the home considering the handicap?** ..... I__I 24

No 0
Yes 1
Which change(s)? : _____

_____

_____

OPTION Evaluation of handicap and family situation may justify a visit to the patient's home.

2.5.3 EDUCATION AND WORK

OPTION It may be valuable to request an evaluation by a centre for educational or social/vocational rehabilitation.

155 **Have actual learning/work skills of the patient been assessed in an educational or vocational context** ..... I__I 25

(eg school, college, previous workplace, industrial retraining unit, etc.)?

No 0
Yes 1
Specify _____

Not necessary 2

156 **Is pre-injury teacher or employer involved in the rehabilitation programme?** ..... I__I 26

No 0
Yes 1
Not feasible 2
Back at work or school 3

157 **Present activity** ..... I__I 27

Full time work 0
Part-time work because of head injury 1
Part-time work for other reasons 2
Vocational education or training 3
School 4
No work or school 5

158 **School/Work: Which description best fits the patient?** ..... I__I 28

- Unaided return to same level 0
- Initially aided return to same level 1
- Same level with additional permanent help 2
- Unaided return to a lower level or part time 3
- Return to a lower level or part time with permanent additional help 4
- Supported employment or placement in school/college for handicapped 5
- No work or school 6

159 **Work earnings** ..... I__I 29
Wages same/more than pre-injury 0
Wages less than pre-injury 1
Therapeutic earnings only 2
Unpaid/voluntary 3
Not working 4

160 **Out of work or school: Which description best fits the patient?** ..... I__I 30
- Proven ability to go to work or school in previous capacity but work or school not available 0
- May be able to go to work or school in previous capacity, but work or school not available 1
- Able to go to work or school in lower capacity, but no work or school available 2
- Return bein arranged 3
- Has been working or going to school but was dismissed 4
- Too early to consider employment options 5
- Unable to go to work or school 6
- Currently working or going to school 7

161 **Tutor** ..... I__I 31
Is anybody appointed to set up and supervise a structured return to school/college work?
No 0
Yes 1
Not necessary 2

Name and qualification : _____

Address and telephone : _____

_____

2.5.4 SOCIAL ASPECTS

162 **Problems with the police** ..... I__I 32
No 0
Yes 1

163 **Alcohol/drug abuse** ..... I__I 33
No 0
Yes 1

164 **Is the patient participating in leisure/ sports activities?** ..... I__I 34
Pre and post injury activities 0
Pre injury activities 1
New post injury activities 2
None 3

2.5.5 MEDICO-LEGAL ASPECTS

165 **Is there somebody to blame for the injury?** ..... I__I 35
No 0
Probably 1
Yes 2

166 **Is there a legal claim for compensation by insurances (social or personal)?** ..... I__I 36

No, impossible 0
No, but possible 1
Yes, being dealt with by insurances (social or personal) 2
Yes, being dealt with by a lawyer 3
Yes, settled by medical or social insurances 4
Yes, settled by a lawyer 5
Other 6
Specify _____

2.5.6 RESOURCES

Attention! The examiner should investigate community facilities for the general public as well as services for people with disabilities and most particularly for the head injured. The examiner is expected to make appropriate recommendations.

167 **Does the patient have an income** ..... I__I 37
(salary, compensation, social allowances or benefits)?

No 0
Yes 1

Specify origin and amount for each resource:

_____
_____
_____

168 **Is there a third person paid to help the patient?** ..... I__I 38

No 0
Yes 1

Specify how many hours a day: _____

Specify qualification: _____

Specify total monthly expenses: _____

169 **Has a "case manager" been appointed to co-ordinate services, help and people required?** ..... I__I 39

None available 0
No, but available 1
No, but someone identified 2
Yes 3
Not necessary 4

Person appointed or recommended:

Name and qualification	Address and telephone
_____	_____
_____	_____
_____	_____

170 **Does the patient attend a centre for people with disabilities?** ..... I__I 40
(Same scoring as for previous item)

Name and address of existing or proposed centre:

_____

_____

171 **Is a support group helping the patient and family?** ..... I__I 41
Not necessary 0
Specifically dedicated to head injury 1
Not specific 2
No association involved or available..... 3

Name and address of existing or proposed support group:

_____

_____

2.5.6 QUALITY OF LIFE

Before recording an answer, say to the patient and informant: "In your present life, are you happy, at ease, satisfied, confortable, making plans? I am asking about all aspects of your present life such as social, work and family. So please rate your satisfaction with life on the scale below".

172 **Patient's quality of life** ..... I__I 42
Enter score (0-6) in box

10 9 8 7 6 5 4 3 2 1 0
I_____I_____I
Very happy Moderately satisfied Not at all satisfied

173 **Informant's opinion on patient's quality of life** ..... I__I 43
(Same scoring as for previous item)

174 **Informant's opinion on his own quality of life** ..... I__I 44
(Same scoring as for previous item)

OPTION These items take inspiration from the Wood-Dauphinee RNLI validated scale (The Reintegration to Normal Life Index - Arch. Phys. Med. Rehabil., 1988, 69, 583-590) which can be used for the patient and the informant.

175 **Scoring on "Glasgow Outcome Scale"** ..... I__I 45
Attention! See Appendix 2 for scoring from 0 to 6.
Good recovery:
Upper level 0
Lower level 1
Moderate disability:
Upper level 2
Lower level 3
Severe disability:
Upper level 4
Lower level 5
Persistent vegetative state 6

2.6 EXAMINER'S CONCLUSIONS

Assessment synthesis

Make a summary, analysing :
- The nature and severity of injury
- The state before the accident (social and vocational situation, personality and illnesses)
- The physical, intellectual and behavioural disabilities, the incapacities and handicaps, the family situation
- The necessary and/or existing resources
- The patient's and informant's final point of view on the situation and needs

Action plan

Indicate your proposals in the following fields:
- Additional investigations
- Medical and/or surgical treatment
- Rehabilitation and case management
- Work and leisure, family and accomodation aspects
- Additional resources (e.g. family, association, transitional centre, etc...)
- Medico-legal and financial aspects
- Patient's and informant's opinions on his new project of life

DATE EXAMINER'S SIGNATURE

Appendix B

Interview study

Patient letter

Consent form

Edinburgh Rehabilitation Status Scale

Community Integration Questionnaire

REHABILITATION STUDIES UNIT

The University of Edinburgh
Charles Bell Pavilion
Astley Ainslie Hospital
Grange Loan
Edinburgh EH9 2HL

Fax 0131 537 9030
Telephone 0131 537 9000
extension

Dear

I am working at the Astley Ainslie Hospital with Dr Brian Pentland, the consultant in charge of your care in this unit a few years ago. We are trying to find out how people who have had a head injury are getting on now. One way to do this is to ask you how your health affects your day-to-day life. We hope that this information will help us improve the service we offer.

If you agree to take part in the project, I would like to speak with you. It would also be helpful if a family member or friend would complete a questionnaire.

Any information you give us will be treated in complete confidence and will not affect any medical treatment you are having. If there is anything that I feel might be helped by further care, I would ask your permission to mention this to your GP. **You are under no obligation to take part in the project, and can withdraw at any time.**

I will phone you in the next few days to answer any questions that you may have about this project. If you are willing, we can arrange a suitable time to meet, either in your home or at the hospital. If you have any concerns about the project that you would like to raise with someone other than myself, Dr Todd (Consultant at Astley Ainslie Hospital) may be contacted. Thank you very much for your help.

Yours sincerely,

Dr Sarah Cudmore
(Medical Research Worker)

Consent form

I agree to take part in a project looking at how my health affects my day-to-day life. I have received a letter about this project, and agree that my GP (or my consultant) may be contacted with any information that is important to my health. Otherwise all information will be treated as strictly confidential.

I understand that I am not under any obligation to take part in this project, and can withdraw without prejudice to further treatment.

Name .....

Signature .....

Signature of researcher ..... Date .....

Edinburgh Rehabilitation Status Scale

1. SUPP - Support Dimension: the frequency and extent to which a person depends on other people AND uses services.

a. The frequency and extent to which he relies on other people for assistance or supervision

Frequency of help from others: expressed in terms of interval dependency (i.e. the length of time a person can manage without assistance or supervision from others).

Extent of reliance on others: described in terms of help or supervision from others in ADL and economic arrangements. This includes the extent of supervision required if the patient is prone to dangerous behaviour.

b. The frequency and extent of services used

Use of services: expressed as a 'hierarchy' in the patient's use of services (GP, home help, district nurse, physio, day care facility etc). This hierarchy extends from 'normal' use of patient's own GP through to inpatient care in Hospital or Nursing Home. Inpatient care prescribes a high level of service use irrespective of the level of independence in ADL.

2. INACT - Inactivity (Occupational and Leisure) Dimension

The frequency and extent of purposeful activity.

This subscale assesses the patient's ability to initiate, sustain and effectively perform the intellectual and physical activity involved in their occupation and/or domestic role and/or leisure pursuits appropriate to his age. There is no emphasis on paid employment. However, if the patient is of working age and not in paid employment due to their disability, his grade may be affected. All patients are rated on their activity over the week. Grading is affected by failure to undertake activities or when effectiveness is reduced as a result of problems with mobility, dexterity, weakness, lethargy, psychological factors etc.

3. ISOL - Social Integration/isolation Dimension

The frequency and extent of social contacts and productive participation in social interaction

This subscale measures the degree and frequency of the patient's participation and sharing in roles, relationships, social networks and communication. The frequency and ease of social function (e.g. in conversation and co-operation with others) will affect the score.

Social and psychological problems associated with any impairment which increases isolation or alienation e.g. disfigurement, or a conspicuous impairment of speech problems are considered. If the patient avoids new relationships or restricts existing ones, the grade allocated will be affected. Contact with others e.g. by use of telephone, letter writing or talking to visitors improves social integration and as such merits a better score.

4. EFFSYM - Effects of Current Impairments/Symptoms Dimension.

The severity and extent to which impairments affect lifestyle.

This subscale rates the severity and constancy of the effect of symptoms and impairments on the individual's lifestyle. All effects are rated, not just those associated with the original diagnosis. The difficulty and distress which occur, and the extent to which they determine the life pattern, influence the grade. The effects are rated from the patient's own experience, clinical assessment, and the behaviour evident to friends or acquaintances. Drug effects may also influence the grade awarded.

Community Integration Questionnaire

Home Integration

1. Who usually does shopping for groceries or other necessities in your household?
2. Who usually prepares meals in your household?
3. In your home, who usually does normal everyday housework?
4. Who usually cares for the children in your home?
5. Who usually plans social arrangements such as get togethers with family and friends?

Social Integration

6. Who usually looks after your personal finances, such as banking or paying bills?
   Can you tell me approximately how many times a month you now usually participate in the following activities *outside your home?*
7. Shopping
8. Leisure activities such as movies, sports, restaurants etc.
9. Visiting friends or relatives
10. When you participate in leisure activities do you usually do this alone or with others?
11. Do you have a best friend with whom you can confide?

Integration into Productive Activities

12. How often do you travel outside the home?
13. Please choose the answer below that best corresponds to your current (during the past month) work situation:

Full time employment (>20 hrs/wk)	Not working, not looking for work
Part time employment (<20 hrs/wk)	Not applicable, retired due to age
Not working but actively looking for work	Volunteer job in the community

14. Please choose the answer below that best corresponds to your current (during the past month) school or training programme situation:

    Full time Part time Not attending school or training programme

15. In the past month, how often did you engage in volunteer activities?

Appendix C

Postal survey

GP letter regarding GOS

Patient letter

Consent form

Feedback sheet

REHABILITATION STUDIES UNIT

The University of Edinburgh
Charles Bell Pavilion
Astley Ainslie Hospital
Grange Loan
Edinburgh EH9 2HL

Fax 0131 537 9030
Telephone 0131 537 9000
extension

Dear Dr

Re: Patient name, address and date of birth

I am a research doctor working with Dr Brian Pentland at the Astley Ainslie Hospital, looking at the long-term consequences of traumatic brain injury. A postal survey has already been undertaken focusing on the individual's own perception of his/her health.

As part of this study, it would be most helpful to have an estimate of any residual disability following the traumatic brain injury for the above patient. I would be very grateful if you would tick the appropriate outcome category and return it to me in the envelope provided. Details of the criteria for the different outcome categories can be found on the accompanying page. All information provided will be treated in complete confidence.

It would also be helpful to know of any changes to the patient's current address.

Yours sincerely

Dr Sarah Cudmore
(Medical Research Worker)

Dr Brian Pentland
(Consultant in Neurorehabilitation)

Appendix C: Postal survey - GP letter regarding GOS

Glasgow Outcome Scale Categories

The categories should refer to deficits acquired as a result of the head injury and should not take account of prior disabilities or other injuries sustained at the same time as the head injury.

DEAD

PERSISTENT VEGETATIVE STATE

SEVERE DISABILITY - Conscious and dependent requiring the help of another person at some time during every 24 hours. Disability may be mental, physical or both.

MODERATE DISABILITY - Independent, i.e. can dress, make a meal, travel on public transport. Some patients may work but at a reduced level.

GOOD RECOVERY - Potentially able to return to work (although may be unemployed). May have some personality change, anosmia, mild dysphasia, trivial residual hemiparesis or cranial nerve palsy.

Thank you very much for your help.

REHABILITATION STUDIES UNIT

The University of Edinburgh
Charles Bell Pavilion
Astley Ainslie Hospital
Grange Loan
Edinburgh EH9 2HL

Fax 0131 537 9030
Telephone 0131 537 9000
extension

Dear

I understand from our records that you were cared for in the Royal Infirmary of Edinburgh in (year), following an accident or injury. A project based at the Astley Ainslie Hospital is interested in finding out how people are getting on now, some years after an accident, by asking some questions about your health today. This information will also help us improve the service we offer.

Any information you give us will be treated in complete confidence and will not affect any medical treatment you are having.

We would be very grateful if you would be willing to fill in the attached questionnaire about your health. It would be helpful for us to know how things are going for you now, and the questionnaire should not take too long to complete. If you feel that you would like a friend or relative to help you fill it in, then that is okay. When you have finished, please use the stamped addressed envelope provided to return the questionnaire to me.

You are under no obligation to take part in this project, and if you have any questions please call me on 0131 537 9234. If you have any concerns about the project that you would like to raise with someone other than myself, Dr Brian Pentland (Consultant Neurologist at Astley Ainslie Hospital) may be contacted. Thank you very much for your help

Yours sincerely,

Dr Sarah Cudmore
(Medical Research Worker)

HEAD OF UNIT Dr Brian Pentland

Consent form

I agree to take part in a project looking at how my health affects my day-to-day life. I have received a letter about this project, and agree that my GP (or my consultant) may be contacted with any information that is important to my health. Otherwise all information will be treated as strictly confidential.

I understand that I am not under any obligation to take part in this project, and can withdraw without prejudice to further treatment.

Name .....

Signature ..... Date .....

Feedback sheet

	Yes	No
Did anyone help you fill in the questionnaire?	☐	☐
Did you find any of the questions upsetting?	☐	☐

Are there any other comments you would like to make?

Appendix D

Publications associated with this thesis

1. Cudmore,S. and Pentland,B. (1996) Early experience of the utility of the European Head Injury Evaluation Chart. *Brain Injury* **10 (7),** 517-529.

2. Cudmore,S. and Pentland,B. (1997) Quality of life in a neurologically disabled population - feasibility of a postal survey. *Journal of Neurotrauma* **14 (4),** 274 (Abstract).

3. McPherson,K.M., Pentland,B., Cudmore,S.F. and Prescott,R.J. (1996) An inter-rater reliability study of the Functional Assessment Measure (FIM+FAM). *Disability and Rehabilitation* **18 (7)** 341-347.

4. McPherson,K.M., Cudmore,S. and Pentland,B. (1997) Assessing disability following brain injury. *Journal of Neurotrauma* **14 (4)**, 274 (Abstract).

5. Cudmore,S.F., Forbes,J.F., and Pentland,B. Physical and mental health subscales of the SF-36 and SF-12 in TBI patients 5-12 years after injury (in preparation)

BRAIN INJURY, 1996, VOL. 10, NO. 7, 517–529

Early experience of the utility of the European Head Injury Evaluation Chart

S. CUDMORE and B. PENTLAND

University of Edinburgh, Astley Ainslie Hospital, Edinburgh EH9 2HL, UK

(*Received 2 May 1995; accepted 21 September 1995*)

The European Head Injury Evaluation Chart (EHIEC) was designed by the European Brain Injury Society to assess head-injured patients from the initial insult to several years following injury. We describe the experience of using the EHIEC in assessing 56 consecutive traumatically brain-injured people admitted to an early inpatient brain injury rehabilitation programme over a 9-month period. An account of its use on admission and at discharge in a subgroup of 40 cases is also given. The difficulties in relation to the length of time to administer the EHIEC, the wording, definition and scoring of items are discussed. We suggest that an instruction manual is required and conclude that, while in its present form it represents a potentially useful checklist, further work is needed to refine the instrument and establish its validity and reliability.

Introduction

Recent years have seen increased awareness of the consequences of head injury and improved rehabilitation services to this group of patients. Accompanying this has been the recognition of the need for serial assessment of functional status to guide clinical practice, scientifically evaluate therapeutic interventions and calculate the economics of brain injury rehabilitation [1–3]. The proliferaton of outcome measures focused on predominantly physical disabilities has been succeeded by more comprehensive tools which take account of psychosocial dimensions which are particularly relevant in this population [4,5]. Most of the more commonly recommended measures, such as the Disability Rating Scale [6], Patient Evaluation Conference System (PECS) [7], and the Functional Independence Measure (FIM) [8] and its derivatives, have originated in the United States, albeit that their adaptation in practice has been international.

The European Brain Injury Society (EBIS), founded in 1989, defined one of its principal aims as the development of a document which was simple, specific and reliable, to evaluate the head-injured patient in a comprehensive manner [9]. The result, the European Head Injury Evaluation Chart (EHIEC), is said to have two main purposes, clinical and scientific. Clinically it should provide information on the individual's impairments, disabilities and handicaps for rehabilitation professionals in practice and for medicolegal purposes. The scientific aims are enhanced knowledge of the natural history of head injury recovery and the evaluation of the efficiency and effectiveness of rehabilitation programmes [9,10]. It is designed to be

Correspondence to: Brian Pentland, Rehabilitation Studies Unit, University of Edinburgh, Astley Ainslie Hospital, Edinburgh EH9 2HL, UK.

0269–9052/96 $12 · 00

simple enough for any rehabilitation professional to use, and to be applicable from initial hospitalization to several years post-injury [10].

We describe the experience of the use of the EHIEC as an assessment instrument in an early inpatient brain injury rehabilitation programme.

Patients and methods

The European Head Injury Evaluation Chart (EHIEC)

The EHIEC comprises 175 items and is divided into two parts. The first section (52 items) details demographic information, the pre-traumatic situation, circumstances of the accident, injuries sustained, initial complications and their management. It is recommended that this part is completed either during the first hospitalization or at a later date from the history and early medical and other records. The second section (items 53–175) covers problems pertinent to impairment, disability and handicap, including the patient's physical, intellectual, affective and behavioural state, as well as simple and advanced activities of daily living, family, social and vocational issues. This section is designed for completion at the initial examination and at regular intervals thereafter. All assessments in this study were completed by one of the authors (S.C.) who is a physician, and who examined and interviewed the patients and primary carers.

Patients

All patients with a diagnosis of traumatic brain injury (TBI) admitted or discharged from the Scottish Brain Injury Rehabilitation Service, Edinburgh between 1 January and 30 September 1994 were assessed using the EHIEC; this comprised 56 patients. Most patients were admitted as direct transfers from acute surgical units, i.e. without discharge home or to a non-hospital setting since injury; their assessments can therefore be considered as being performed during the first hospitalization. The exceptions were eight people who had their injuries over 1 year prior to admission. A subgroup of 40 of the 56 had the EHIEC completed at both admission and discharge from the unit, to allow some assessment to be made on the sensitivity of the instrument.

Results

Section 1

The first section of the chart is based on a survey of the acute medical records, supplemented where necessary by further enquiry of medical attendants, relatives or other carers and the patient himself, or herself. Items 1–11 relate to basic demographic details. Thus the median age of the 56 patients was 31 (mean 36·1; SD 15·8) years; 45 (80%) were male. Prior to the incident 37 (68%) were living in their own home, 16 (29%) with parents, two had been in hospital care and one came under the category 'other', as he lived in a hostel. Occupation is classified into seven categories, and occupational status into nine. Two summarize this, 16 were in unskilled or partly skilled occupations, 38 in skilled or higher categories while it was not possible to classify two; 34 were in full-time or part-time work at the time

of the accident. The next group of items (12–22) describe the pretraumatic situation, such as past medical history, pre-existing disabilities and social problems, by the use of yes/no questions, and will not be presented, for the sake of brevity.

Items 23–25 document the type or cause of accident, whether or not it was related to work or travel to or from work, and whether there were other victims. In the study population 32 (57%) had had road traffic accidents; 11 (20%) had either been injured at work or on the journey to or from work; and in four (7%) of the cases there was another serious or fatal victim. The following three items are the worst score on the Glasgow Coma Scale (GCS) in the first 24 hours; the coma length measured by 'days to obey simple commands'; and post-traumatic amnesia (PTA), which is the 'interval from injury to regaining continuous day-to-day memory'. GCS scores were between 3 and 8 in 35 (62·5%); 9–12 in seven (12·5%) and 13–15 in 14 (25%) of the 56 subjects. Data on length of coma were obtained for 53 (95%) of the subjects, and in 13 this was less than 1 day, in 24 between 1 and 28 days and in 16 more than 28 days. Post-traumatic amnesia results are presented in Table 1.

The next part of the EHIEC (items 29–52) is under the paragraph heading 'Initial Management', although in fact it also serves as a record of complications and other injuries as well as details of management. The responses to these items vary from dichotomous yes/no categories to eight category codes for 'site of major damage (haematoma or other)' (item 36). In order to present these data in summarized form the responses are abbreviated to no, or none or yes if referring to an injury or complication, in Table 2.

Section 2

The second part of the EHIEC is headed 'Follow-up', although it is suggested it be completed along with part 1 at first hospitalization, and thereafter at intervals of follow-up. Items 53–60 log details of which examination is referred to, the date, current living circumstances and length of stay in various possible settings. There follows a listing of complications (items 61–68) which are coded as absent or present, with further qualification in some instances; medications (items 69–74) coded no or yes; and current clinical management (75–82). Table 3 summarizes the findings in abbreviated form. The reason that there are positive responses for all items 75–80 reflects the fact that the study was done in a post-acute inpatient

Table 1. Post-traumatic amnesia as recorded by EHIEC (n = 56)

Length of PTA	Number of subjects	Percentage of total
0–1 hour	1	1·8
1 hour–1 day	3	5·4
1–7 days	5	8·9
8–14 days	2	3·6
15–28 days	7	12·5
29–60 days	10	17·9
> 60 days	16	28·6
[Unassessable]†	12	21·4
Total	56	21·4

†Unassessable is not an EHIEC code, but no useful estimate of PTA was possible.

Table 2. EHIEC items 29–52 (abbreviated) (n = 56)

Item no.	Description	No/none	Yes	Data unavailable
29	Tracheostomy	29	25	2
30	Assisted ventilation	17	39	0
31	Early sedation†	17	39	0
32	Deterioration in conscious level	43	12	1
33	Basal fracture	46	10‡	0
34	Other fracture†	25	31	0
35	Penetrating injuries†	56	0	0
36	Haematoma†	28	25	3
37	Other lesions (not haematoma)†	19	32	5
38	Site of major damage (haematoma or other)†	8	33	15
39	Neurosurgical intervention (excluding ICP monitoring)†	38	18	0
40	Cardiovascular†	48	7	1
41	Pulmonary†	19	35	2
42	Infection (not pulmonary)†	41	13	2
43	Thorax	38	16	2
44	Abdomen	47	9	0
45	Pelvis†	48	8	0
46	Spine†	49	7	0
47	Right upper limb†	46	10	0
48	Left upper limb†	42	13	1
49	Right lower limb†	44	12	0
50	Left lower limb†	43	13	0
51	Injuries to face/jaw†	27	28	1
52	Burns	56	0	0

†Includes more than a yes/no response.
‡Includes four diagnosed on clinical evidence only.

rehabilitation setting where management includes assessment and treament by all these disciplines.

The next subsection is headed: 'Impairment, Disabilities' and is subdivided into Physical State (83–97), Cognitive Status (98–116), and Affective and Behavioural State (117–130). To illustrate the nature of the information provided two items have been selected from each of these subdivisons: hemiparesis (item 86) and visual acuity problems (item 91); attention (item 98) and writing (item 104); patient's grief and mourning (item 124) and patient's motivation (item 126). Full information on all 56 cases is presented, together with the cohort of 40 patients who were assessed both on admission and at discharge from the rehabilitation unit, in order to give some indication as to whether the EHIEC showed change over time. The findings are presented in Tables 4–6, in which the term 'total group' refers to the initial evaluation of all 56 cases and 'admission' and 'discharge' describe the subgroup of 40 cases.

It will be noted that in a proportion of cases items are unassessable. Such a code does not appear in the EHIEC but, for some items, there is a code for 'other', and space allowed for specification of what that amounts to.

Subsection 2.5 of the EHIEC is Disability and Handicap, and starts with 'Activities of Daily Life' grouped into basic (131–136) and advanced (137–142), with items 143–145 relating to the need of a third person.

Table 3. EHIEC items 61–82 (n = 56)

Item no.	Description	No/none	Yes	Data unavailable
Complications				
61	Post-traumatic epilepsy†	42	12	2
62	Fit frequency†	42	12	2
63	Meningitis†	53	2	1
64	Hydrocephalus†	52	3	1
65	Chronic subdural haematoma†	53	1	2
66	Urinary†	42	13	1
67	Cutaneous†	47	9	0
68	Other complications	40	15	1
Current medication				
69	Anticonvulsants	46	10	0
70	Major tranquillizers	52	4	0
71	Benzodiazepines	49	7	0
72	Antidepressants	52	4	0
73	Analgesics	27	29	0
74	Other	38	18	0
Current clinical management				
75	Physiotherapy	0	56	0
76	Occupational therapy	0	56	0
77	Speech therapy	0	56	0
78	Psychology/psychiatry	0	56	0
79	Rehabilitation physician	0	56	0
80	Social work	0	56	0
81	Other therapy	56	0	0
82	Surgery†	21	35	0

†Includes more than yes/no response.

The ADL coding instructions are as follows:

0 = Normal/Independent
1 = Independent but some diminution (e.g. slowness or need for technical help)
2 = Partly independent (needs human help or stimulation some of the time)
3 = Severe dependence (needs human help or stimulation most of the time)
For each item, score if any of the problems is present.

The individual items are listed in Table 7 with the median, mean and range of scores for the 56 cases presented. For the 40 people in the subgroup where admission and discharge data were available the mean sum score for basic ADL items (six items, possible score range 0–18) was 8·8 on admission and 5·6 at discharge; for advanced ADL (six items; possible score range 0–18) it was 13·1 and 10·6. Taking all 12 items the mean admission total score was 21·9 and at discharge 16·2.

The remaining parts of the EHIEC within the Disability and Handicap subsection address the following issues: Family, Relatives and Accommodation (items 146–154); Education and Work (items 155–161); Social (items 162–164) and Medicolegal Aspects (items 165–166); Resources (items 167–171), which refers to support agencies; and finally Quality of Life (items 172–175). The latter comprises

Table 4. Physical state: frequency of 'impairments, disabilities' on EHIEC

EHIEC item	Total group ($n = 56$)	Admission ($n = 40$)	Discharge ($n = 40$)
86. Hemiparesis (with or without spasticity)			
None	24	17	20
Right: mild/moderate	2	1	1
Left: mild/moderate	8	5	7
Right: severe	1	1	2
Left: severe	3	3	0
Mild: double hemiparesis	6	4	3
Severe on one side	10	7	5
Severe on two sides	2	2	2
Other central paralysis	0	0	0
91. Visual acuity			
None	41	27	28
Right: mild/moderate	0	0	0
Left: mild/moderate	3	2	2
Right: severe	0	0	0
Left: severe	1	1	1
Bilateral moderate	1	1	1
Bilateral severe	4	3	3
Combination	1	1	1
[Unassessable]†	5	5	4

†Not an EHIEC category.

Table 5. Cognitive status: frequency of 'impairments, disabilities' on EHIEC

EHIEC item	Total group ($n = 56$)	Admission ($n = 40$)	Discharge ($n = 40$)
98. Attention			
None	26	14	21
Mild/moderate	13	11	11
Severe	17	15	8
104. Writing			
No problem	19	14	15
Mild motor problem	4	2	5
Severe motor problem (unreadable writing)	4	1	1
Mild/moderate impairment of spelling or syntax	8	5	7
Severe impairment of spelling or syntax	3	2	1
Combination	5	5	2
[Unassessable]†	13	11	9

†Unassessable due to visual, motor or cognitive problems or due to unresponsiveness.

Table 6. Affective and behavioural state: frequency of 'impairments, disabilities' on EHIEC

EHIEC item	Total group ($n = 56$)	Admission ($n = 40$)	Discharge ($n = 40$)
124. Patient's grief and 'mourning', rebuilding a new identity			
Satisfactory acceptance	20	11	23
Insufficient acceptance	16	13	11
No acceptance	5	3	1
[Unassessable]†	15	13	5
126. Patient's motivation			
Clearly engaged	40	29	27
Mild/moderate engagement	15	10	12
No engagement	1	1	1

†Not an EHIEC category.

three visual analogue scales and a Glasgow Outcome Scale. Our results for these 30 items are rather variable, as one might anticipate in a population largely consisting of early post-injury cases still undergoing inpatient rehabilitation. Most patients in this study had been hospitalized since the time of injury, and issues such as need for respite care for the family could not be answered. Similarly while still in early rehabilitation it was often too early to determine whether housing adaptations would be required. The whole question of vocational or educational activity and potential was often difficult to assess at this early stage post-injury. Quality of life measurement in hospital was felt to be of dubious relevance, although recordings were made; for these reasons the data are not presented here. However, a further study is under way assessing these same people in the community some time after discharge.

Table 7. Disability and handicap: basic and advanced activities of daily living on EHIEC (n = 56)

EHIEC item	Median	Mean	Range of scores
131. Eating/drinking	0·0	1·0	0–3
132. Sphincter control	0·0	1·1	0–3
133. Toileting	2·0	1·4	0–3
134. Dressing	1·0	1·4	0–3
135. Transfers	1·0	1·3	0–3
136. Mobility at home	1·0	1·4	0–3
137. Mobility outside the home	2·0	1·9	0–3
138. Going out shopping	2·0	2·0	0–3
139. Using public transport	2·0	2·0	0–3
140. Driving a car	3·0	2·9	0–3
141. Writing a letter	2·0	1·8	0–3
142. Financial management and administrative tasks	2·0	1·7	0–3

Experience of completing EHIEC

There were a number of difficulties encountered in using the chart, which might cause potential difficulties when implementing it into routine use. These related to the length of time required to complete the EHIEC, the wording of the questions, the definition and scoring of items, and the structure of the EHIEC.

Time to complete EHIEC

Retrieving the initial information from medical records of the acute management of the patient was often very time-consuming. This involved locating these records from a number of neurosurgical and orthopaedic units and then searching for the relevant details. While ideally such information should be readily available, and might be made easier to obtain should acute units adopt a procedure to chart EHIEC data, it is unlikely that all referring units would conform to this. Interviewing both the patient and the principal caregiver took between 1 and $1\frac{1}{2}$ hours, on average. Thus the total time to complete the chart was of the order of 2–3 hours for each case.

Wording of questions and definitions of items

Although the meanings of individual items are often self-evident from their title, this is frequently not the case, and there appears considerable scope for subjectivity in interpreting them. In Section 1, for instance, the 10 items under the heading 'Pre-traumatic situation' are preceded by the sentence: 'In your clinical judgement, is there pre-traumatic evidence of major disabling conditions/problems, with significant functional consequences?' This may be relatively easy to judge for items such as prevous head injury or psychiatric problems treated by a specialist (items 14 and 15). However, what constitutes 'addiction (alcohol/drugs)' (item 17) or 'pre-existing mental disability' (item 19)? Both addiction and learning disability have diagnostic criteria which take time and effort to apply precisely. Substance abuse and poor school performance are common in TBI patients, and it can be difficult to judge whether these amount to the diagnosis mentioned or, indeed, whether or not they caused 'significant functional consequences' pre-morbidly.

Similar ambiguity occurs in Section 2. An example is 'oral understanding' (item 101) which is determined by the question: 'Does he/she have difficulty (aphasia) in understanding what is said to him/her?' Whether this is specifically directed at recording only the presence/absence of receptive dysphasia, or whether it includes other difficulties in understanding, is not clear. Spatial/temporal orientation (item 105) is rated according to whether the subject can 'give the exact date, and name of the place of examination (name of hospital or centre)?' Clearly, the individual who can name the hospital may well be far from spatially oriented. Within behavioural items, 'Mental excitement, talkativeness' (item 118) is judged by the question 'does he/she talk rapidly and excessively without making much sense'. All behavioural assessments are by their nature somewhat subjective and therefore require the criteria to be more precise than this example.

Another issue that requires clarification is the concept of the 'third person' in relation to activities of daily life (items 143–145). Items 143 and 144 ask whether the patient needs help from a third person for physical reasons or for cognitive/

behavioural reasons respectively. Does this include the assistance of a second family member with, for instance, lifting and handling or restraint, or does it imply the need for help from outwith the immediate primary carer(s)?

Coding and scoring items

The method of scoring items relates closely to the above issue of wordings and definitions. This is most apparent with the use of the terms mild, moderate and severe. Indeed, most commonly in the EHIEC the division is between 'mild/moderate' and 'severe'. This is frequently found in the Impairment, Disabilities, section, where mild/moderate 'means that independent daily function is still possible in basic activities of daily living' and severe 'prevents such independence in at least one of those activities'. Table 4 lists the coding for hemiparesis (item 86). It can be difficult to differentiate mild/moderate hemiparesis (code 1 if on the right, 2 if on the left) from severe hemiparesis (codes 3 and 4 respectively). Code 5 = 'mild double hemiparesis' while 8 = 'other central paralysis (paraparesis, tetraparesis)'. A double hemiparesis is presumably a tetraparesis, and again what constitutes 'mild' is not defined. Similar criticisms are relevant for the following item (87): spasticity. Both muscle power and spasticity are impairments for which clinical scales exist, albeit that they are crude, yet few guidelines are given.

With regard to activities of daily living, a footnote reference is made to the Functional Independence Measure (FIM) [8], suggesting that it may be justified in 'severe handicap, particularly physical'. Apart from the fact that the FIM is directed principally at disability not handicap, no guidance is given as to the incorporation of the results into the EHIEC.

Particular problems were encountered with the majority of items relating to the patient's Behavioural and Affective State (items 117–129). The instruction to this section are as follows.

> Problems are only scored as present if they have appeared or increased since the injury. Exceptions are indicated for specific items. Otherwise, code as follows:
> 0 = None
> 1 = Reported by the informant, regarding the past month (patient's opinion is excluded in this section)
> 2 = Observed by the examiner
> For each item, score if any of the problems is present.

For example, the informant (carer/relative) may report a very severe behavioural problem in one of the categories listed, but this problem may not be evident to the examiner during the 30–45 minutes of the examiner's interview with the patient. In such circumstances the patient should be graded 1. On the other hand an individual, reported as of even temperament and exhibiting no abnormal behaviour at home, may show mild symptoms of distress, anxiety or irritation under the stress of interview. Such a person should be coded 2, according to the criteria. While one appreciates that the EHIEC is perhaps designed to simply differentiate between informant and examiner's opinions on behaviour and affect, it would seem more valuable to have some more detailed ranking of these items.

Structure of the EHIEC

The importance of obtaining information from the informant, as well as directly from the patient, is accepted as a valuable feature of the EHIEC. However, it is unclear whether joint interviews with patient and relative should be held or the interviews be done separately. For some groups of items in Section 2 there is a mixture of questions and tests in adjoining items which made administration of the tests somewhat cumbersome. A re-ordering of the items to allow for separate interviews with the patient and informant was useful in some cases.

In addition to the four areas described above, ease of use of the EHIEC can vary with the severity of injury. In this study the initial assessment took place during early inpatient brain injury rehabilitation, and it was found that full cognitive assessment was not always possible due to visual, motor or language impairments. Data collected by the originators of the EHIEC were primarily on very severe TBI (GCS 3–5), although the time between injury and assessment is not stated [9–12]. At the other end of the spectrum, when assessing mild TBI, it is unclear whether defects in higher-level functioning would be adequately tested for by the EHIEC. For example, 'Attention' is assessed subjectively by the examiner, and therefore a problem with mild distractibility may go unnoticed. Such difficulties can have significant consequences for the individual patient. It is acknowledged, however, that measures such as the EHIEC do not replace the need for detailed and expert neuropsychological assessment.

Discussion

Measurement tools are most easy to devise when they are measuring a single phenomenon for a single purpose. The consequences of brain injury are so protean that developing a comprehensive tool is exceedingly difficult. This difficulty is greatly magnified when it is designed to serve many purposes. Add to this the intention that the EHIEC be suitable for use by a wide range of professional staff, in different settings over a prolonged period of time, and it is apparent how ambitious the aims of its originators were. This study describes the experience of a single investigator looking principally at early post-injury cases.

The first section of the EHIEC as outlined provides useful documentation of the premorbid state, the circumstances and extent of injuries and some aspects of initial management. Although such information is often provided in published studies of head-injured patients, it is not collected in as much detail in the other major functional assessment scales [4–7]. This is perhaps to be expected as it is not, strictly speaking, functional data that are being collected. There is merit, however, in recording such data in a systematic way, as a number of those evaluating outcomes have recommended [3,13,14]. Where the rehabilitation facility receives all its patients from a single acute neurotrauma centre it should be feasible to encourage the use of the first section in the admitting unit. This is particularly relevant to the three items of GCS score, coma length and post-traumatic amnesia (PTA), which assist in grading severity of injury. Clearly some people are transferred to rehabilitation while still in PTA but this does not alter the principle of attempting to document these three factors routinely. With these items, however, as with many others in the EHIEC, there is a need for more rigid and unambiguous guidelines for measurement. Although the worst GCS score within the first 24 hours has been

recommended by some [15], others have argued that the best score be used [14]. There are cogent arguments for the use of the GCS 6 hours after presentation, to allow for such variables as the identification and treatment of associated injuries and the reduction in the effects of alcohol, drugs or hypothermia [16]. Length of coma is often defined as duration of GCS less than 9 [14,17] rather than simply days to obeying simple commands other than only eye-opening as recommended in the EHIEC. Despite debate on the accuracy of PTA measurement, it is still generally regarded as a useful measure of severity of injury [14,18] and has been recently shown to correlate with MRI evidence of brain damage [19]. The EHIEC document does recommend the use of the Galveston Orientation and Amnesia Test (GOAT) [20], administered repeatedly to determine emergence from PTA for scientific study. This is the practice in our unit for post-acute cases but, as others have noted [21], it is impractical for those admitted to rehabilitation at a later stage.

The second, 'Follow-up', section of the EHIEC comprises 122 pieces of information. Unlike the first described above, it is recommended for serial use and is purported to be sensitive to change in functional status. It is said to be both valid and reliable, although there is little published evidence to support this [11,12]. Several items have face validity, and are common to other head injury outcome measures [5–7]. Thus within the subsections headed 'Impairment, Disabilities' and 'Disability and Handicap', which in total account for 82 items, attention is paid to physical, communicative, cognitive, affective and behavioural consequences of brain injury. In addition, similar, for instance, to the PECS [7], information is documented on family and social resources. There are few omissions of what would be considered likely and relevant topics. The most unsatisfactory aspect, however, in respect of its use as a functional assessment tool is its lack of sensitivity for most items. This is explained by the authors of the EHIEC on the basis that, by using dichotomous responses, it should be easy to use by untrained staff and have higher inter-rater reliability [10]. This may be so, but such a design severely limits its potential for monitoring change, especially in the earlier stages of recovery, as was the subject of this study and is reflected in our findings with the subgroup assessed on admission and at discharge from inpatient rehabilitation. However, it must also be acknowledged that the originators of the EHIEC have suggested that it may be complementary to other head injury outcome scales, and should be used in association with them [10,12].

Mention has already been made of the need for a more detailed instruction manual, to clarify the definition and scoring of items. Despite the rough guidelines provided to differentiate mild/moderate from severe categories in Section 2, the terms mild, moderate and severe appear as separate categories for scoring certain items. The use of this terminology is notoriously inconsistent in rehabilitation practice, especially with regard to cognitive impairments, and is best avoided unless strictly defined [22]. Guidance is also needed on how to collate and present the data recorded. At present there is no standardized manner in which to extract information in summarized form. It provides rather, in its shortest form, a 12-page record of scores, albeit amenable to computer storage. Some components may be suitable for numerical sum scoring or presentation routinely in histogram form. Such methods might enhance its usefulness by assisting interprofessional communication of information within the rehabilitation team.

In its present form the EHIEC provides a potentially useful checklist for case record purposes, but a major drawback to its routine use in clinical practice is the

2–3 hours needed to complete it. In this study a research worker, who was supernumerary to the clinical team, performed the task. Even if referring acute hospitals could be persuaded to document reliably the demographic, incident and initial management details, the process would be time-consuming. If the wording of certain items were clarified, and the scoring system reviewed such that all members of the rehabilitation team were capable of rating items, and the load could be shared, this might reduce the time needed. These factors would also need to be addressed if the information gathered by the EHIEC was to be shared by team members to assist them in planning the rehabilitation programme for the individual concerned. In addition, further refinement of the scoring system is required so that the instrument can be demonstrated to be sensitive to change, particularly as it is recommended that it be completed at regular intervals over the first 3 years after injury. Currently therefore its clinical utility appears very limited. Overriding all these considerations is the need for more validity and reliability studies.

An alternative approach to revising and developing the EHIEC in its present form might be to consider extracting useful components of it, and amalgamating these data with one or other of the global assessment scales emerging from the United States of America. As our world becomes an increasingly smaller place, and communication improves, we may yet devise a literally global head injury assessment schedule.

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